DOCTOR OF PHILOSOPHY

Understanding the hidden experience of head and neck cancer patients a qualitative exploration of beliefs and mental images

Lang, Heidi

Award date:
2010

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University of Dundee

UNDERSTANDING THE HIDDEN EXPERIENCE OF HEAD AND NECK CANCER PATIENTS: A QUALITATIVE EXPLORATION OF BELIEFS AND MENTAL IMAGES

A dissertation presented for the degree of

Doctorate of Philosophy at the University of Dundee

by

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(BA Hons Applied Social Sciences)

University of Dundee, October 2010

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GLOSSARY OF TERMS AND ABBREVIATIONS

[Please also see note regarding this terminology on page 5 of Chapter 1]

Mental image	Any image which is perceived by the patient as existing in their mind's eye. Mental images may be realistic or figurative in nature (see below).
Explicit image	A mental image as above which is acknowledged explicitly by the patient.
Implicit image	Any conception or understanding of the cancer which refers to it as having a physical form which *may* be envisaged in the mind's eye, but is not explicitly acknowledged by the patient as a mental image.
Realistic image	An image which conveys a literal representation, that what the patient actually perceives something to look like (regardless of the its factual accuracy).
Figurative image	An image which conveys a non-literal representation of what something looks like.. Figurative images may be: • Metaphorical – where an object or 'thing' is regarded as symbolic or representative of something else. • Allegorical – can be interpreted to reveal a less blatant meaning. • Abstract – does not attempt to represent reality, but rather conveys meaning through subtleties of form (e.g. shape, colour).
Visual concepts / conceptions (embedded in language)	The representation of an object or concept by way of a visual image that suggests a particular association or point of similarity. This term is used exclusively in relation to language which conveys a realistic or figurative image (referred to as 'visual language').
Visual knowledge	Refers to knowledge, understanding or beliefs which are embedded in or represented by explicit or implicit mental images and visual concepts embedded in language (in contrast to non-visual knowledge - see below). This is the collective term for mental images and visual concepts embedded in language.

Non-visual / words-based knowledge	Knowledge, understanding or beliefs which is perceived to arise form words, numbers and verbal description only, and which is not embedded in images.
Illness representation	The patient's mental representation or understanding of their illness. This comprises both a cognitive representation and an emotional representation.
Cognitive representation	Beliefs about the illness. May include beliefs about the identity, cause, consequences, timeline, and curability/ controllability.
Emotional representation	Feelings about the illness.
Illness beliefs / illness perceptions	Specific ideas or aspects of the patient's understanding of their illness

CMT	Conceptual metaphor theory
EEG	Electroencephalograph
FMRI	Functional magnetic resonance imaging
HNC	Head and neck cancer
HP	Health professional
HPV	Human papilloma virus
MI	Myocardial infarction (heart attack)
PET	Positron emission tomography
SRM	Self-regulation model

ACKNOWLEDGEMENTS

With thanks of the greatest magnitude to my project supervisors – Professor Brian Williams and Dr Mary Wells from the University of Dundee, and Professor Gerry Humphris from the University of St Andrews – who developed and collaborated on this project, and all of whom provided guidance and support beyond the call of duty. Also to those within the SDHI and School of Nursing departments who have helped the project (and me) along the way, particularly Rosanne Bell, Alison Harrow, Sara Joice and Ruth Dryden. And to the Chief Scientist Office (CSO) Scotland who funded this studentship.

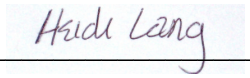
Sincerest thanks to the patients and partners who took part in the research studies, who provided invaluable contributions to the project by sharing their experiences with me, and without whose tolerance of the shortcomings of a novice researcher there would be no thesis. And with grateful thanks also to the health professionals from NHS Tayside and NHS Grampian who collaborated on the project, facilitated recruitment, and participated in the pilot study for this thesis.

Finally a big thankyou to my family and friends for their support and patience, and for enduring with only a wry smile my endless boring on about the project. And especially to Big Chief Hobbit, who courageously resisted the recurring urge to file for divorce throughout the process of this research.

Respectfully dedicated to those patient participants who have since died; and in memory of Alasdair, and the little one.

AUTHORS DECLARATION

I declare that I am the author of this thesis and that the research it describes has been done by me. All references cited have been consulted and all quotations have been distinguished by quotation marks and the sources of information clearly acknowledged. This thesis has not been accepted in any previous application for a degree.

Signature 

Date 30th September 2011

Heidi Lang

I certify that Heidi Lang has completed the equivalent of nine terms of experimental research and that she has fulfilled the conditions of the relevant Ordinance and Regulations of the University of Dundee, so that she is qualified to submit this thesis in application for the degree of Doctor of Philosophy

Signature 

Date 30th September 2011

Dr Mary Wells

ABSTRACT

Patients' beliefs about their illness are known to influence their experiences of illness, its psychological impact, their health behaviours, and overall health outcomes. Research into illness beliefs has typically involved written or oral methods, yet recent studies have suggested that patients' beliefs about their illness may be embodied in visual form, in their mental images of the disease. Beliefs embedded in mental images may not be captured via traditional modes of assessment, and thus far the possible significance of this kind of 'visual knowledge', has been largely overlooked. Studies using visual methods to explore patients' mental images suggest this is a viable and useful approach which may provide additional insights into their illness beliefs. Research of this kind is in its infancy however, and there are several fundamental questions concerning the existence and nature of mental images, how best to access such images, and their relationship to illness beliefs, which are as yet unanswered. This thesis employed qualitative methods to address these issues and explore the significance of mental images within the context of head and neck cancer. It consists of three empirical phases – a methodological pilot study, a qualitative meta-synthesis, and a longitudinal study. The findings indicate that many patients do generate a mental image of their cancer, and this is significant in terms of their understanding of both the disease and its treatments. Images appear to enhance patients' comprehension of what is going on inside their bodies, and may both reflect and influence illness beliefs. In this thesis these findings are considered with reference to the methodological issues intrinsic to researching mental images, and the implications for future research and clinical practice.

1 THESIS OVERVIEW

The remit of this thesis was to explore the existence, meaning and potential significance of patients' mental images of their disease within the context of head and neck cancer. A qualitative approach was adopted to address three fundamental aims: 1) to investigate suitable methods of accessing and externalising mental images, 2) to clarify the nature and properties of such images, and 3) to examine the significance of mental images in terms of their relationship to patients' illness beliefs and experiences. The context of this research is explicated in two chapters. First a short literature-based introduction to head and neck cancer is provided (Chapter 2). The following chapter first delineates fully the underpinning theoretical basis of the thesis, Leventhal's self-regulation model drawn from health psychology, and presents some pertinent literature stemming from this model which demonstrates the importance of patients' beliefs about their illness. The interest in mental images of disease is located within this theoretical framework with reference to a small body of emerging research in this area. It goes on to provide an overview of the concept of mental images drawn from cognitive psychology/ neuroscience, and then review how mental images have thus far been explored in research into patients' beliefs and experiences of disease. Existing approaches to externalising and analysing patients' mental images are also recounted, and from this literature review specific research questions are identified (Chapter 3).

There are three empirical components to this thesis – a methodological pilot study, a qualitative meta-synthesis, and a larger longitudinal research study. The philosophical and theoretical underpinnings of the thesis are outlined in the subsequent chapter (Chapter 4), alongside the methods employed in the two research studies (the meta-synthesis is literature-based and the distinct approach to this is presented in the relevant chapter). The pilot study (Chapter 5) was primarily concerned with investigating the

acceptability and feasibility of the proposed methods of accessing the hidden realm of patients' mental images of their cancer, and the findings informed the direction of the larger study. The next empirical phase, a meta-synthesis of qualitative research into the experience of head and neck cancer, represents an interpretation of a body of work, and provides a context in which to consider the role of patients' mental images. This endeavour is reported in two chapters. First the background and methodological approach to the synthesis is delineated (Chapter 6), and then the findings are presented and related to relevant theory (Chapter 7). The final empirical phase, a larger longitudinal study, further examines the role of mental images in terms of patients' understandings and experiences of cancer, and includes greater attention to visual concepts embedded in language and the relevance of images to how treatments were understood, as well as of the development or evolution of patients' mental images over time. The account of this phase comprises two further chapters. The rationale, refined scope, and the methods used in this study are first recounted (Chapter 8). The subsequent chapter then conveys the findings pertaining to the nature and characteristics of patients' mental images of their cancer and treatments, their relationship to illness beliefs, and significance in terms of patients' overall understandings (Chapter 9). The concluding chapter of the thesis (Chapter 10) draws on the collective findings of this thesis to reflect on the pervasiveness of mental images and other visual concepts in understanding cancer, and the argued function of such images in enhancing patients' comprehensions of what is going on inside their bodies. The place of mental images in relation to patients' non-visual (words-based) beliefs about their disease is explicated in terms of Leventhal's self-regulation model which formed the primary theoretical basis for this project; and argued subtle differences in the ways in which images represented the cancer and treatments are clarified. The methodology is reconsidered, and limitations of the thesis and the implications of the findings for research and clinical practice delineated.

1.1 THEORETICAL FRAMEWORK AND THE RATIONALE FOR INVESTIGATING MENTAL IMAGES OF CANCER

The theoretical grounding of this thesis is in the self-regulation model (Leventhal, Meyer & Nerenz, 1980), and it is within this framework that mental images are considered as a feature of the psychological experience of illness. This model proposes that in the context of illness three interactive psychological processes are consciously engaged: interpretation and the generation of a mental representation ('illness representation') of the problem, implementation of coping strategies, and appraisal of the efficacy of these strategies. The concept of 'illness representations' comprising a set of beliefs about the illness (a cognitive representation), and an emotional response to it (an emotional representation), is central to the self-regulation model as it is thought to guide the individual's subsequent behaviour. Since the publication of this theory an extensive body of research has confirmed that an individual's illness representation can influence their experiences of illness, its psychological impact, their health behaviours, and overall health outcomes. It is surprising therefore that there is little research into the illness beliefs of patients with cancer, given the incidence of cancers in the population and the enormity of the psychological impact of the disease. An emerging field of research has demonstrated that patients' beliefs about their illness may be embodied in visual form, in patients' mental images of their disease, and that such images may too influence patients' experiences. The prevailing mode of investigating patients' illness representations is through written or oral (i.e. words-based) assessments which may not capture beliefs embodied in mental images, and thus far this dimension of patients' experiences, the possible significance of this kind of 'visual knowledge', has been largely overlooked. Yet recent studies suggest that using visual methods to explore patients' mental images of illness is a viable and potentially useful approach which may provide additional insights into their illness representations. As research of this kind is in its infancy, studies involving visual methods are scattered across different disciplines, and

there are several fundamental questions concerning the phenomenon of mental images which are as yet unanswered. These issues include the manner and extent to which people may visualise their illness, how best to externalise such images, the nature of these images, and their relationship to illness beliefs. This thesis will attempt to address these questions by collating existing research into mental images of illness, utilising visual methods to access patients' mental images, and exploring the nature and potential importance of images in the context of patients' understandings of (that is their 'illness representations') and experiences of their disease.

1.2 RATIONALE FOR THE STUDY POPULATION: HEAD AND NECK CANCER AS AN IDEAL CONTEXT FOR RESEARCH INTO PATIENTS' MENTAL IMAGES

Cancer is a disease whose language is pervaded with images and metaphors, and psychological factors are known to have an important impact on the patients' experiences and a range of outcomes. Head and neck cancer (HNC) may present unique threats to the individual's well-being, as both the disease and treatments can induce significant functional impairments, and combined with the visibility of the disease can severely impair patients' sense of self, social functioning, and quality of life. Compared to other cancers there is a lack of research into patients' experiences of HNC, despite the high rates of psychological morbidity and prevalence of problematic health behaviours amongst this patient group. This population is therefore in great need of interventions to enhance psychological well-being and address harmful behaviours to maximise both quality and quantity of life. However the apparent lack of qualitative research with this patient group means little is known about their subjective experiences of the disease, insight which is an essential precursor to the development of appropriate interventions.

1.3 A NOTE ON 'IMAGE' TERMINOLOGY

The glossary preceding this chapter defines the terminology used in the thesis with respect to images. Although this is included at the outset of this thesis for purposes of clarity a number of these terms were actually created as the thesis developed in response to the literature and the empirical work carried out. The employment of different terms as the thesis developed is clarified at the appropriate points throughout the chapters of the thesis.

1.4 CHAPTER SUMMARIES

The following section presents brief chapter summaries in order to demonstrate the inner logic, sequence and narrative of the thesis.

1.4.1 CHAPTER TWO: INTRODUCING HEAD AND NECK CANCER

Chapter two provides an introduction to the head and neck cancer patient population. It begins by briefly outlining the incidence and aetiological profile of the disease – head and neck cancers are strongly associated with alcohol consumption, tobacco smoking and low socio-economic status – and the radical treatments employed in tackling it. The impact of the disease/treatments on physical functioning and the nature of the psychosocial issues faced by these patients are delineated with reference to the extensive quantitative quality-of-life literature. Head and neck cancer patients constitute a highly appropriate group for this kind of exploratory qualitative research as their experiences are under-researched, the disease is associated with poor psychological functioning, and the often visual nature of their illness may have hitherto unexplored implications for how it is represented in mental images.

1.4.2 CHAPTER THREE: EXPLICATING THE IMPORTANCE OF ILLNESS BELIEFS, PATIENTS' MENTAL IMAGES OF THEIR DISEASE, AND EXISTING APPROACHES TO ACCESSING THESE

Chapter three demarcates the theoretical background to the thesis as described earlier in this chapter. A fuller account of Leventhal's self-regulation model is provided, and relevant literature which has examined patients' illness beliefs in accordance with this theory[1] in relation to their psychological well-being, health behaviours, and overall health outcomes is then presented. Existing research which has examined patients' images, primarily as a means of communicating experiences of illness, is outlined, and the notion of what is meant by a 'mental image' defined It is argued that knowledge may be visual as well as words-based in nature, and the potential power of visual knowledge in the form of images is discussed with reference to some of the sociological and psychological evidence. The findings from the critical subset of the literature which has examined patients' mental images in relation to their illness beliefs are then detailed, findings which, suggest that accessing patients' mental images of their illness may be a viable way of assessing their illness beliefs, and may also add another dimension to our insight into patients' understandings and experiences of their disease. Existing methods of externalising and analysing patients' mental images of disease are explicated alongside some criticisms pertinent to the use of visual methods such as drawing in research. Finally specific research questions for this thesis are identified, concerning the existence, meaning, and importance of patients' mental images of their disease. These are:

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[1] Some of the literature presented in this chapter stems from a second prominent theory which characterises the psychological response to illness in terms which echo the concept of illness representations - Kleinman's concept of 'explanatory models'. This theory has been similarly influential in the galvanisation of research into illness beliefs, and its congruence with Leventhal's notion of illness representations allows research carried out under both perspectives to be presented in this chapter. A brief overview of the complementary theory of explanatory models follows the substansive account of the self-regulation model in this chapter.

1. In what ways and to what extent do patients with head and neck cancer visualise their cancer?
2. What forms do patients' mental images of the cancer take (i.e. anatomical, metaphorical, abstract)?
3. What are the origins of these images?
4. What is the relationship between patients' mental images of their cancer and their illness beliefs?

1.4.3 CHAPTER FOUR: DEVELOPING THE METHODOLOGICAL APPROACH

Chapter 4 delineates the methodological approach to the thesis. The focus of this research on the subjective meaning of patients' mental images of cancer, and how this pertains to their experiences, demanded a qualitative approach. The thesis was developed from a constructivist perspective, which emphasises the relative, subjective nature of reality. Eschewing the existence of an objective reality which can be measured, constructivism proposes that people construct the meaning of their lives, and 'truth' and reality are in fact interpretations from the individual's subjective, relative standpoint. Drawing on elements of Heidegger's phenomenology – the focus on context, the relative nature of interpretation, and the researcher's role in constructing and determining the data generated from research – qualitative methods were employed to address the aims of the thesis. Chapter 4 elucidates the methodological perspective of the thesis and clarifies how the concept of illness representations drawn from the self-regulation model informed this research in conjunction with this overarching perspective. The methods adopted in the execution of the first and third empirical phases of the thesis – a pilot and larger qualitative research study – are justified in this chapter and relevant ethical considerations are put forward. The second empirical phase, a meta-synthesis of existing research, was literature-based and thus has a distinct methodological design, and this is reported separately in Chapters 6 and 7.

1.4.4 CHAPTER FIVE: ACCESSING THE HIDDEN REALM OF MENTAL IMAGES OF CANCER – A METHODOLOGICAL PILOT STUDY

Chapter 5 reports the design and findings of a small pilot study carried out to test the acceptability of image re-creation within the context of a research interview, and to provide preliminary data to inform the development of the larger subsequent study. A sample of six HNC patients, two of their partners, and four relevant health professionals participated in semi-structured interviews, and the findings confirmed the feasibility of the proposed methods for externalising patients' mental images of their cancer. This study indicated that some patients do indeed have mental images of the cancer, and that these both influenced and embodied their understanding of the disease. It also appeared that images embedded in visual language may play a role in patients' comprehensions of treatments, and that the interpretation of the impact of various treatments may produce changes in the mental image of the cancer. These key findings underpinned the development of the third empirical phase of the thesis which is reported in Chapters 8 and 9, a longitudinal study exploring patients' mental images of the cancer with greater attention afforded to images conveyed in language, and those pertaining to treatments, and the evolution patients' mental images over time. The pilot findings also revealed the largely hidden nature of patients' mental images. These images appeared to be a private phenomenon and were not discussed with family or clinicians, despite their apparent importance in terms of patients' beliefs and embedded nature of mental images in patients' broader experiences. This finding provided the impetus for the development of the second empirical phase of the project – a meta-synthesis of existing qualitative studies – to clarify what has been reported about these patients' experiences, to examine whether any evidence of the existence of such images is present in the existing literature, and to provide a context in which to further consider the role of patients' mental images.

1.4.5 CHAPTER SIX: A META-SYNTHESIS OF QUALITATIVE STUDIES OF THE EXPERIENCE OF HEAD AND NECK CANCER – PAPER IDENTIFICATION AND APPRAISAL

Chapter 6 outlines the relatively new field of synthesising qualitative work, a controversial endeavour to which there are a range of possible approaches. Noblit & Hare's (1988) seminal 'meta-ethnography' method guided our approach, and this is justified in the context of a divergence of methodological opinion. The implementation of the first three of the five broad stages of this method is detailed in this chapter. These three stages comprise the data collection element of the synthesis in terms of identifying those papers to be included. First the scope of the synthesis is defined and an appropriate search strategy developed (stage one). Following this the systematic search of the literature and process of screening the retrieved records, including critical appraisal, is described (stage two). The search strategy consisted of three complementary search strings implemented in seven databases, and retrieved 114,311 records. After initial screening by title, and then abstract, 109 full texts were reviewed by the research team to establish potential relevance. This resulted in the retention of 48 papers, which were then critically appraised by two independent reviewers to determine inclusion or exclusion, concluding stage two. The chapter closes with an overview of the characteristics of the fifteen papers which survived quality appraisal to be included in the synthesis, in which the methods and findings of the papers are explicated (stage three).

1.4.6 CHAPTER SEVEN: A META-SYNTHESIS OF QUALITATIVE STUDIES OF THE EXPERIENCE OF HEAD AND NECK CANCER – ANALYSIS AND FINDINGS

Chapter 7 details the analytical part of the process of synthesising the papers' findings. This incorporates the relating of the studies' findings and translation of the original concepts across the papers to identify the key concepts which encompass the whole

(stage four). Finally these key concepts are refined and synthesised (stage five) to produce the findings of the meta-synthesis which represent a secondary interpretation of the body of research. This chapter goes on to present these findings in the form of six core themes. Three themes characterise the reality of living with head and neck cancer – 'living and waiting: betwixt and between', 'disruption to daily life', and 'the diminished self'. Three further themes represent how patients negotiate the experience – 'making sense of the experience', 'sharing the burden', and 'finding the path'. The findings are then related to some of the relevant theory regarding patients' experiences of serious illness. This analytical phase was carried out concurrently with the large empirical study reported in Chapters 8 and 9, and two themes in particular resonated with the findings of the latter study – the penetrating uncertainty of living with HNC and undergoing the treatments ('living and waiting'), and patients' apparent drive to form a coherent understanding of their situation ('making sense of the experience'). The significance of these aspects of the experience is considered further, in relation to the existence of mental images, in the final chapter of the thesis which draws together the findings of each component of this research.

1.4.7 CHAPTER EIGHT: THE LONGITUDINAL STUDY – METHODS, SCOPE AND RATIONALE

Chapter 8 opens by re-examining the three potential study designs identified through the findings of the pilot study. The main longitudinal study sought to address the research questions identified in Chapter 3 in more detail and with a more extensive and diverse sample. In addition, it explored the evolutionary aspect of patients' beliefs and mental images of the cancer from cancer diagnosis and through treatment via data collection at two time-points. Informed by the pilot findings, the focus of this study was expanded to incorporate greater attention to visual concepts embedded in language and how images may pertain to patients' understandings of treatments, though the primary focus

remained mental images of the cancer. The study methods are explicated in this chapter, with particular reference to the refined methods for externalising internal mental images.

1.4.8 CHAPTER NINE: THE LONGITUDINAL STUDY – FINDINGS

Chapter 9 presents the findings of this research study. The first section provides a profile of the twenty-five study participants, including demographic details, location of the cancer, and classification of the range of different treatment modalities undertaken. Nineteen participants completed two interviews – one in the early stages of treatment, the other after treatment completion. Three patients withdrew after the first interview, and three patients died, and thus a total of 44 interviews were carried out. The remainder of the chapter recounts the findings as they pertain to the original research questions concerned with the nature and characteristics of mental images of the cancer, the perceived origins of these images, and how they relate to patients' illness beliefs. The findings are presented in four parts. Part one details the range and form of mental images of the cancer reported by participants and their apparent origins. Additional methodological issues concerning the external representation of internal mental images are raised as the majority of patients declined to re-create their mental image pictorially. In particular some of those patients who conveyed an image verbally did not acknowledge this as a mental image in line with the original definition adopted for the thesis, and it is argued that this suggests that mental images may exist on a continuum being more implicit or explicit in nature. The variety of images of the cancer is clarified in terms of their level of sophistication; and a tentative but potentially important pattern in the data is reported which suggests there may be a relationship between levels of anxiety and social engagement and the conceptualisation of the cancer as a 'destroyer' or a rival life force.. This part closes with the identification of three key influences over how patients' visualise their cancer. Part two relates aspects of patients' mental images to specific illness beliefs concerning the severity and identity or meaning of the cancer. It

demonstrates the emotional power of beliefs embedded mental images and comments on the potential role of images in patients' perceptions of the likely consequences or outcomes of their disease. Part three of the findings delineates how images also appeared to be involved in how patients' understood their treatments. Patients' mental images of the cancer were integral to this, however there appeared to be subtle differences in the types of image which represented treatments. Compared to mental images of the cancer, images pertaining to treatments did not constitute complete or definitive representations – rather particular aspects of patients' beliefs were embedded in multiple distinct images, and so treatments were perceived visually in a more fragmented fashion. Treatments also did not seem to be visualised independently of the patient's mental image of the cancer, rather treatment-related images were applied to the image of the cancer. In light of these subtle distinctions, images pertaining to treatments are characterised in nature as visual concepts embedded in language which conveys realistic or figurative images, rather than discrete mental images visualised in the mind's eye[2]. Finally, part four of this chapter reports on how patients' mental images of their cancer evolved as new information, particularly the perceived impact of treatments, was assimilated into these existing images. The findings of the longitudinal study outlined here form the basis of the following discussion chapter which explicates the apparent function of mental images and visual concepts embedded in language in the context of patients' broader understandings and experiences of head and neck cancer.

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[2] Given the previous assertion that mental images of the cancer can exist implicitly and that these are revealed through visual concepts embedded in language it could be argued that images pertaining to treatments are simply further implicit mental images. However it is the fragmented or incomplete nature of these images, and the manner in which they appear to be employed only in relation to the image of the cancer, which suggests that the proposed distinction is warranted (i.e. it does not appear to be the case that patients may have discrete, implicit mental images of the treatments as per the those of the cancer), and this interpretation is discussed further in Chapter 10.

1.4.9 CHAPTER TEN: DISCUSSION, CONCLUSION AND IMPLICATIONS FOR PRACTICE AND FURTHER RESEARCH

The final chapter of the thesis expands further on the specific role of visual knowledge, in the form of explicit or implicit mental images of the cancer, and visual concepts of treatments, as important in enabling patients to 'answer' two key questions – 'what is the cancer?', and 'what is going to happen?' Drawing together the empirical findings of all three phases of this research, the argument is presented that the experience of cancer is characterised by uncertainty, and in this context patients appear to strive to understand the particular nature of their disease and treatments in an attempt to predict the outcome. Mental images of the cancer appear to serve primarily to furnish the patient with a tangible, comprehensible identity for their disease, countering the potential ambiguities of a verbal diagnosis ('what is cancer?'). The question of what is going to happen (in terms of the consequences of the cancer and perceived outcome of treatments) seems to be addressed in an ongoing fashion, and this is reflected in the responsive nature of patients' mental images of the cancer which evolve as new information received by the patient – including information imparted by clinicians and their own interpretations of changes in symptoms – is assimilated into the patient's existing image and associated understanding of their disease. This evolving understanding enables the patient to mentally 'keep track' of the progress of their treatments, and to generate hypotheses about the likely outcome, which counteracts some of the uncertainty inherent to the experience. Images, especially mental images of the cancer, appear to be important in facilitating this ongoing comprehension of what is going on inside the patient's body. Patients interpret a variety of information to formulate a sense of what is likely to happen, and the key types of information which affect the development or evolution of their mental image are delineated in this chapter. The question of whether patients' mental images or beliefs about the cancer come first is

also considered, and there appears to be a bi-directional relationship between beliefs and mental images, each informing and influencing the other.

Chapter 10 goes on to relate these findings to the theoretical framework underpinning the thesis in terms of Leventhal's self-regulation model and the concept of illness representations and specific dimensions of illness beliefs in particular; and the apparent utility of mental images in increasing the coherence of patients' understandings of what is going on inside their bodies. It is proposed that patients may generate a mental image of their cancer as one element of their cognitive representation of the disease – i.e. that this cognitive representation incorporates both their non-visual words-based beliefs and a visual representation of the cancer in the form of a mental image – and that these images may both influence, and be influenced by, their beliefs and associated emotional responses. The proposed distinction in the manner in which patients appear to visualise their cancer and treatments is then discussed with reference to the argument for the existence of implicit mental images which are not consciously perceived by the patient. The interpretation of images conveyed in language as indicating an underlying mental image, and in particular the assertion that such images are not merely linguistic expressions but represent the utility of images in understanding the cancer and, more especially, visual conceptions of treatments is then discussed in relation to conceptual metaphor theory. This is a prominent, but contested, theory emanating from cognitive linguistics/psychology which proposes that people think about and understand abstract concepts in terms of metaphors, and that the nature of metaphor is fundamentally conceptual rather than linguistic in nature.

The latter part of this chapter reflects on the methodological issues inherent to researching mental images as they pertained to the research studies carried out for this thesis. Addressing the first stated aim of the thesis, to investigate methods of accessing

internal mental images, this includes discussion of the challenges in externalizing such images, and the advantages and disadvantages of pictorial versus verbal representations of internal mental images. The potential influences of methodological factors over patients' accounts of their mental images of the cancer , such as the process of communicating the image to a third party, are also considered. Limitations of the thesis in terms of its design, the study samples and data collected, and the possible impact of the concurrent undertaking of phases two and three of the research on the findings are presented. The penultimate section of chapter ten identifies the implications of the thesis findings for clinical practice, particularly in respect of communication about cancer and the hidden nature of patients' mental images of their disease, and identifies potential avenues for further research.

The findings of the thesis support the growing body of research which suggests that patients' illness beliefs may be embodied in their mental images of their disease, and that such images appear to be significant in terms of the patient's broader understanding and experience of their illness. The thesis concludes that patients' understandings of their disease may comprise both visual and non-visual (words-based) components, and that by neglecting to address the former in terms of patients' mental images this important aspect of, and influence over, their experiences will continue to be hidden from view.

2 INTRODUCING HEAD AND NECK CANCER

The purpose of this chapter is to provide a short introduction to head and neck cancer. The term 'head and neck cancer' actually refers to a range of different cancers within the head and neck region, but tends to exclude malignancies of the central nervous system. A comparatively rare group of cancers in the UK, the disease affects more men than women, and the survival rates have not improved significantly over the past ten years, though site-specific statistics do show some tendency towards improvement. The aetiology of head and neck cancers is dominated by environmental factors – tobacco smoking, alcohol consumption, and low socioeconomic status. Treatment for HNC requires a multi-disciplinary approach, and the multiple modes of treatment patients may undergo are outlined. Due to radical treatments, HNC patients may experience significant impairments to functioning and quality of life, and the latter part of this chapter presents some of the relevant physical and psychosocial issues as expounded in the extensive quality-of-life literature. The chapter closes with a commentary on the limitations of quantitative research in terms of enhancing our understanding of the subjective experience of head and neck cancer.

2.1 INCIDENCE AND MORTALITY

The five most common cancers of the head and neck region – oral, laryngeal, thyroid, nasopharyngeal, and other pharynx cancers – account for approximately 7.2% of all cancer cases worldwide (excluding skin cancer) (Parkin, Bray, Ferlay & Pisani, 2005). Environmental factors play a significant role in the development of malignancies at specific sites within the head and neck, and so incidence rates vary widely by country and site. Cancers of the nasopharynx for example are far more common in South-East China and North Africa than in countries of the Western world, while laryngeal cancers

occur more frequently among European, South American, and Western Asian populations (Parkin, Pisani, & Ferlay, 1999).

In the UK head and neck cancers (HNC's) are comparatively rare, with approximately 8,000 people diagnosed annually (Cancerbackup, 2006). In Scotland, cancers of the head and neck account for 5.9% and 2.0% of male and female cancers respectively (NHS Scotland, December 2009). Unlike a number of other cancers, the 5-year survival rate for head and neck cancers has remained relatively stable over the past decade (General Register Office for Scotland, 2006). In Scotland current 5-year survival rates for head and neck cancer patients stand at 54.7% for males, and 60.7% for females (ISD Scotland, 2009). Over the period 2001-2005, there were 1,301 male deaths and 516 female deaths registered in Scotland as a result of head and neck cancers (General Register Office for Scotland, 2006). It is suggested that the comparatively poor improvement in survival may be due to the dwindling number of malignant growths of the lip – which carried an exceptionally positive prognosis when compared to other head and neck tumour sites. Overall, however, site-specific figures do suggest a tendency towards improved survival (NHS Scotland, December 2009).

2.2 WHAT IS HEAD AND NECK CANCER?

The term 'head and neck cancer(s)' can be problematic, not simply referring to all malignancies within the head/neck region. As a general rule, brain and eye tumours are excluded from the definition, and are grouped with those of the spinal cord, as cancers of the central nervous system (CNS). Thyroid cancer is less straightforward, sometimes included within the HNC group, sometimes regarded separately (Davies & Welch, 2006). Sources are not always explicit about which sites are excluded from their definition, and statistical references may refer to all HNCs, or for example oral cancer and thyroid cancer as distinct groups. The term 'head and neck cancer(s)' used herein will

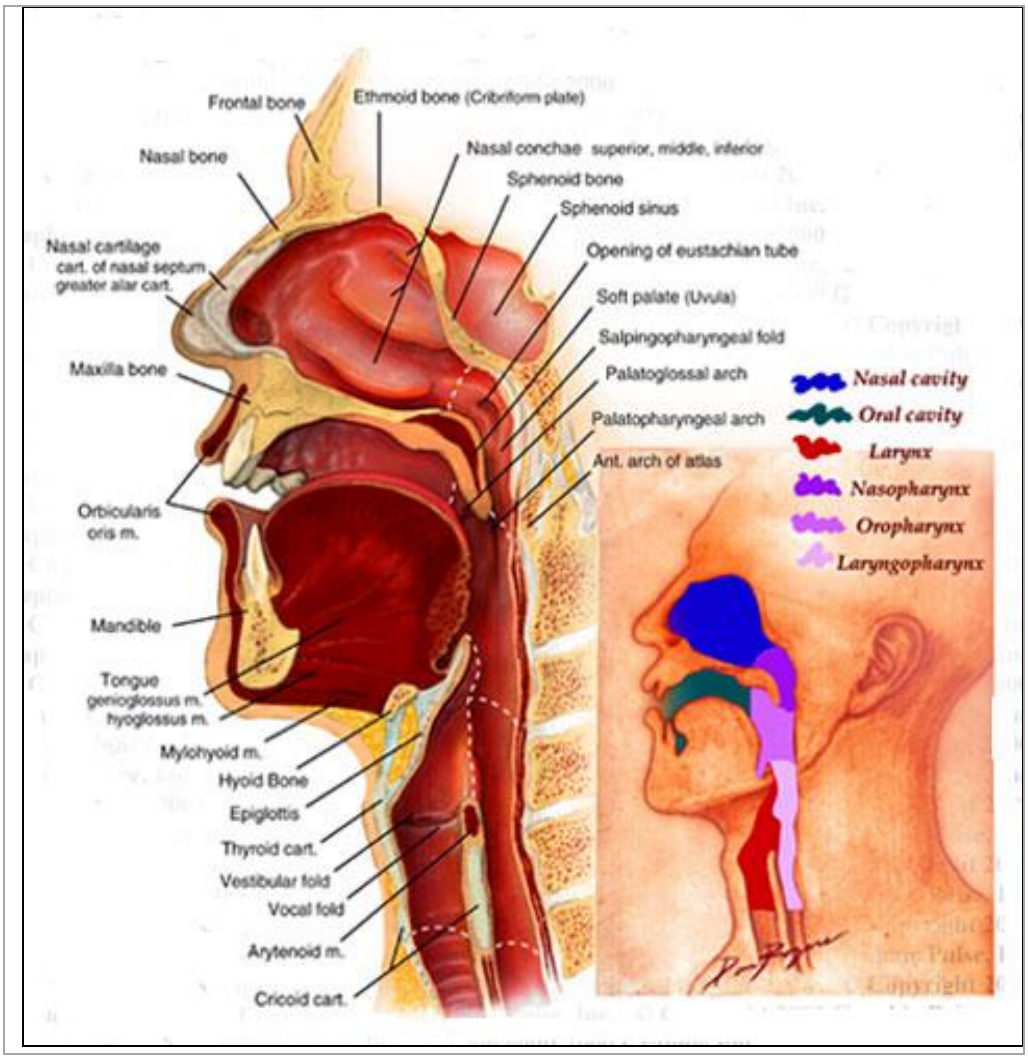
therefore refer to all malignancies within the head and neck region except the brain, as is consistent with most HNC definitions.

Within the head and neck region, the most common anatomical sites for malignant growths are located within the oral cavity, the tongue, the pharynx, thyroid gland, and larynx. A recent estimation of the prevalence in the UK per site is shown in table 1, and these sites are located in their anatomical context in figure 1.

Table 1 - No. cases diagnosed annually in the UK by anatomical site (Cancer Backup, 2006)

Site	**No. cases per year**
Larynx Voice-box – Below the Pharynx in the neck	2,200
Pharynx Tube runs from behind the nose to the oesophagus and trachea. 3 parts: nasopharynx behind the nose; oropharynx includes the back of the mouth, base of tongue and tonsils; and the hypo-pharynx is the lower portion.	1,650
Oral cavity Including the mucosal lining of the cheeks and lips, the floor and roof of the mouth, and the gums.	1,400
Thyroid gland	1,400
Tongue	1,250
Paranasal sinuses Cavities in the bone around the nose.	500
Saliva glands	500
Nasal cavity	400

Figure 1 - Location of sites in their anatomical context (Graphic Pulse Inc., 2000)



2.3 THE AETIOLOGY OF HEAD AND NECK CANCERS

Environmental factors are critical in the aetiology of head and neck cancers. Smoking, alcohol, and low socioeconomic status/deprivation are empirically established risk factors for the disease. However there is increasing interest in the role of dietary habits, in particular low consumption of fruit and vegetables. Recent epidemiological evidence has also identified the Human Papillomavirus (HPV) as a distinct aetiological factor pertinent to a small subset of head and neck cancers. Each of these will now be outlined briefly in turn

2.3.1 TOBACCO SMOKING

Nearly 70% of all head and neck cancer cases can be attributed to tobacco smoking – either independently or in conjunction with alcohol drinking – according to a recent analysis of the pooled data from 18 case-control studies across the Western world. The site-specific proportion of cancers attributable to smoking in the head and neck region varies, for example tobacco alone is estimated to account for approximately 25% of cancers of the oral cavity, but over half (52%) of laryngeal cancers (Hashibe, 2010).

In relation to specific head/neck cancers, tobacco smoking has been consistently and substantially associated with laryngeal cancers (Rafferty, Fenton & Jones, 2001), and those of the pharynx and oral cavity (Kuper, Boffetta, & Adami, 2002). All modes of tobacco use elevate risk of HNCs; smoking cigarettes, cigars and pipes in the western world, alongside the use of various kinds of oral smokeless (chewing) tobacco popular in countries of the still-developing world (Kuper, Boffetta, & Adami, 2002; Johnson 2001).

Importantly, a dose-response relationship in terms of duration and intensity of smoking has been observed, and so even heavy long-term smokers may cut their risk of HNCs by reducing or stopping smoking. For example, after a period of cessation for 10 years for oral and pharyngeal cancers, and 15 years for laryngeal cancer, the risk declines to nearly that of people who have never smoked (Kuper, Boffetta, & Adami, 2002).

Cessation following a diagnosis of head and neck cancer is vital, as continued smoking increases the risk of recurrence or development of a second primary tumour (Do et al, 2004). Smoking tobacco also reduces the efficacy of treatments such as radiotherapy (Browman et al, 1993). Despite this however, many head and neck cancer patients continue to smoke throughout and beyond treatment. For example a recent study reported approximately 1 in 5 of the 210 HNC patients followed-up one year after

diagnosis continued to smoke, though this did represent a great reduction in smoking behaviour as 50% of the sample were current smokers at the time of diagnosis (Duffy et al, 2008). One reason which has been posited for patients' continued smoking is its self-medicating properties against the considerable psychological distress experienced (Tromp et al, 2005).

2.3.2 ALCOHOL CONSUMPTION

Alcohol consumption is also strongly associated with head and neck cancers. Generally it is regarded that the greater the intake, the greater the risk of developing a head and neck cancer (McCaffrey et al, 2007; Freedman et al, 2007). Analysis of data pooled from 14 case-control studies has indicated that consuming more than three alcoholic drinks daily brings a twofold increase in the risk of head and neck cancers for never-smokers, affirming its status as an independent risk factor (Hasibe, 2010). Though as per tobacco use, the type of alcohol consumed has not yet been established as significant in terms of risk (Viswanathan & Wilson, 2004; Purdue et al, 2009).

The recent increase in HNCs amongst women in the UK is considered by many authors to be primarily due to the increase in female alcohol consumption, and these authors present a convincing case showing census data illustrating the trend for greater female drinking alongside the greater numbers being diagnosed with HNCs (Viswanathan & Wilson, 2004). Indeed among women aged over 40 years, it has been reported that the risk from alcohol for cancers of the oral cavity and oropharynx surpasses the risk from smoking (Sanderson et al, 1997). As with continued smoking, alcohol intake throughout and beyond treatment is associated with a greater risk of recurrence and secondary tumours – particularly at those sites which are directly exposed to the alcohol as it is drunk (Viswanathan & Wilson, 2004).

2.3.3 SMOKING AND ALCOHOL COMBINED

In combination, tobacco use and alcohol consumption have a synergistic effect on risk (Johnson, 2001; Rodriguez et al, 2004), an impact greater than multiplicative (Hashibe et al, 2009). Many studies have reported that heavy drinking is strongly correlated with smoking - both pre- and post-diagnosis (Duffy et al, 2008; Vander Ark, DiNardo, & Oliver, 1997), with the risk from alcohol magnified in accordance with increasing tobacco smoking (Sanderson et al, 1997; Hashibe, 2010). The causal power of tobacco and alcohol combined is roughly equal to that of tobacco smoking alone – accounting for 35% and 33% of cases respectively – but it greatly exceeds that of alcohol alone – which is estimated to account for only 4% of all head and neck cancers (Hashibe et al, 2009).

2.3.4 LOW SOCIOECONOMIC STATUS

Epidemiological studies demonstrate a higher incidence of, and mortality from, head and neck cancers amongst deprived or lower socioeconomic groups. ISD Scotland (2004) report an incidence of 11 cases per 100, 000 amongst those in the least deprived quantile, with the rate steadily increasing up to 22 per 100,000 in the most deprived quantile. Mortality rates increase, and 5-year survival rates decrease, in line with increasing deprivation.

While deprivation ratings have been independently associated with survival rates, behavioural factors weigh heavily in the equation with people in lower socioeconomic groups more likely to smoke tobacco (Jarvis & Wardle, 2006, p227; Scottish Government, September 2009), and men more likely to consume greatly excessive

amounts of alcohol[3], or to drink 'very heavily' (defined as >50 units of alcohol/week in the Scottish Health Survey 2008 - Scottish Government, September 2009, p56). Additionally, deprived populations are more likely to have a poor diet lacking in fresh fruit and vegetables, which has also been implicated in the aetiology of HNCs (Edwards & Jones, 1999). Presentation at a later stage of the disease is another problem associated with this demographic, and this has been confirmed as a powerful factor behind the socioeconomic differences in mortality from cancer, along with differences in treatment according to class (Woods, Rachet, & Coleman, 2006).

2.3.5 POOR DIET

Several studies have reported that low intake of fresh fruit and vegetables is related to an increased risk of oral and pharyngeal cancers (Silverman, 2001; Rodriguez, 2004), and a lack of specific antioxidant vitamins in the diet has also been associated with higher risk of head and neck cancers (Suzuki et al, 2007), though the precise role of dietary factors is as yet uncertain. Prevalence of a poor diet is often observed among deprived populations, which suggests poor nutrition may be associated via other coexisting contributory factors such as greater tobacco and alcohol consumption, and a less pro-active approach to their own health (Edwards & Jones, 1999).

2.3.6 THE HUMAN PAPILLOMAVIRUS

Independent of the aforementioned environmental factors, a sexually transmitted virus - the Human Papillomavirus (HPV) – has more recently been identified as causal factor in a particular subset of head and neck cancers in its own right (Ragin, Modugno, & Gollin, 2007; Goon et al, 2009). Already known to play a role in cervical cancer, HPV

[3] For women, income and socioeconomic status appear to be inversely related to alcohol consumption (Scottish Government, September 2009)

produces benign tissue growths such as warts (Weller & Wells, 1990), some strains of which can progress into cancerous lesions. Transmittable via oral sex, an increased risk of tonsillar and oropharyngeal cancers has been reported (Hobbs et al, 2006), and two meta-analyses have estimated the proportion of cancers of the oral cavity, pharynx, and larynx positive for the HPV virus at around one-quarter to one-third of all cases (Kreimer et al, 2005; Termine et al, 2008). Patients with HPV+ cancers tend to be younger in age, and have a better clinical prognosis, and do not necessarily share the typical (deprived) demographic profile of head and neck cancer patients (Goon et al, 2009; Westra, 2009).

HPV cases aside, the predominant aetiological background of most head and neck cancers – smoking, alcohol, and low socioeconomic status – dictates that many patients hail from a context of deprivation, difficult life circumstances, and a predisposition towards psychological morbidity associated with alcohol abuse (Mehanna & Morton, 2006). These patients must then endure a lengthy treatment regime and an array of debilitating side effects/functional impairments caused by the radical treatments employed in HNC management, which further compromise psychological well-being. An overview of the treatment of head and neck cancer and some of the difficulties imposed on patients follows.

2.4 THE TREATMENT OF HEAD AND NECK CANCERS

Due to their location and associated dysfunction, head and neck cancers require a range of specialists to be involved in both treatment and rehabilitation. The NHS is moving towards becoming a more integrated service, and multi-disciplinary teams (MDTs) comprising a range of specialists (oncologists, radiologists, surgeons, pathologists, clinical nurse specialists, dieticians etc) are being set up at the heart of head and neck cancer

services, responsible for assessing, planning treatment for, and managing each HNC patient (NICE, 2004).

Along with this multi-disciplinary approach to disease management, use of multi-modal treatment regimens for head and neck cancers is increasing (Bridgewater & Spittle, 2000). Treatment usually comprises surgery and/or radiotherapy, and there is increasing use of concomitant chemotherapy – that is chemotherapy delivered concurrent to radiotherapy ('chemoradiation') – which has been consistently shown in randomised trials to improve survival (Munro, 1995; Bhide et al, 2010). However, multiple modes of treatment also intensify the treatment burden on patients, concomitant chemotherapy exacerbating the acute side effects of radiotherapy for example (Nguyen et al, 2002; Choong & Vokes, 2008).

2.4.1 RADIOTHERAPY

Radiotherapy regimens differ in length and dosage according to the specifics of the disease. In head and neck cancer, external beam radiotherapy involves the targeting of x-rays to converge at the site of the malignancy, guided by use of a mould or mask which is made especially for each individual. This mask is affixed over the neck and head region, and secured to the table to minimise movement and ensure correct targeting (Cancerbackup, 2005). Radiotherapy sessions are short - a matter of minutes - but require daily visits to the hospital for a period of several weeks. This routine becomes increasingly demanding over time due to the debilitating fatigue induced by the accumulative treatment (Faithfull, 2006).

Side effects local to the irradiated area also worsen as treatment progresses. A range of oral/pharyngeal symptoms which impair the ability to eat normally and can severely compromise patients' nutritional status are of particular concern. Oral morbidity may

include mucositis - inflammation and ulceration of the tissues (Scully, Sonis, & Diz, 2006), dryness of the mouth due to saliva gland dysfunction (xerostomia), difficulty/pain on swallowing, alterations in or loss of taste sensation, and seizing of the jaw muscles (trismus) (Shaw, 2001). In addition to considerable pain and discomfort, these symptoms impair speaking and eating, and are key factors in weight loss during and after radiotherapy (Lees, 1999). Often the capacity to eat is impaired – or projected to be impaired – to such an extent that the patient is unable to maintain adequate nutrition orally, and requires a PEG (Percutaneous Endoscopic Gastrostomy) feeding tube to be fitted (Hayward & Shea, 2009). Insertion of feeding tubes may in itself be problematic however, with the potential to induce a range of major and minor complications such as internal bleeding and infections at the site, and – according to a recent systematic review of 2379 patients – a procedure mortality rate of around 2% of head and neck cancer patients (Grant et al, 2009).

While the current impact of side effects from radiation is severe, the development of intensity-modulated radiotherapy (IMRT) holds great promise for reducing the burden of side effects on radiotherapy patients. This technique enables the radiation to be concentrated more precisely on the target area, thereby reducing the toxicity to non-cancerous surrounding tissues and lessening resultant functional morbidity. For example preservation of the salivary glands reducing xerostomia, and preservation of certain muscles diminishing swallowing impairment (Bhide et al, 2010).

2.4.2 CHEMOTHERAPY

Chemotherapy is the administration of cytotoxic drugs in repeated cycles of a dose followed by a rest period of up to a few weeks (Cancerbackup, 2006). Like radiotherapy, the particular drugs and dosage used is dependent on the specifics of the disease (Coward & Coley, 2006). Chemotherapy may be utilised as an inductive or

adjuvant therapy – that is prior to, or after, site-specific treatment in the form of radiotherapy/surgery; or concomitantly, alongside radiotherapy (known as 'chemo-radiation'). Concomitant chemotherapy is increasingly used to treat head and neck cancer as its superior efficacy has been borne out by comparative trials (Pignon et al, 2009). Chemotherapy amplifies radiotherapy-induced morbidity (Nguyen et al, 2002; Choong & Vokes, 2008), and can cause extreme nausea and vomiting, anaemia, and bone marrow suppression (neutropenia), which means the patient is more vulnerable to infections (Silverman, 1999; Choong & Vokes, 2008).

2.4.3 SURGERY

Surgical treatments range from straightforward excision of the tumour – which is often necessary to optimise prognosis – to more extensive procedures, perhaps incorporating removal of lymph nodes, restoration of affected structures, or removal of internal structures such as fat and muscle tissue, bone, nerve, and cartilage (Munro & Stafford, 2007). In cases of radical surgeries, in addition to the inevitable scarring, the bulk, shape, and appearance of aspects of the head and neck can be transformed, and physical functioning can be dramatically impaired.

Such impairments, together with the psychological ramifications of living with visible disfigurement mean that the disease may have considerable social consequences for the patient also. For example, in cases where removal of the larynx or voice-box is necessary patients must learn both to breathe through a surgically created opening in the neck (NICE, 2004), and alternative methods of speech. With reference to the latter it has been reported that only 40% of patients recover a manner of speech to a standard where they are able to effectively use the telephone (Munro & Stafford, 2007).

Speech is also compromised by non-laryngeal operations. For example, recovered speech following surgery to the oral cavity or oropharynx is often perceived by patients to be "deviant" despite moderate-good objective ratings of intelligibility. These concerns tend to be outweighed by the impairment to swallowing/eating resulting from such surgery however, which is reported to affect quality of life more severely (Kreeft et al, 2009). Another common surgery-specific impairment is shoulder dysfunction following neck dissection – removal of lymph nodes and soft tissue from one or both sides of the neck. The pain or restricted mobility which results negatively impacts activities of daily living and quality of life (Stuiver et al, 2008).

Latent side effects may present months or years following chemotherapy (Coward & Coley, 2006), and difficulties in eating and speech often linger on beyond the course of radiotherapy and may become chronic problems for patients (Shaw, 2001). Patients who also undergo surgery for their cancer may therefore have to live with permanent functional impairments such as these in addition to those which may be incurred by radical surgery.

This section has illustrated some of the treatment-induced difficulties head and neck cancer patients may face. The impact of the disease and treatments can be enormous, affecting the most basic aspects of human functioning. However, in order to understand this on an individual level it is necessary to first consider the cultural context in which patients experience the disease.

2.5 CANCER IN WESTERN CULTURE

Cancer itself can be said to be imbued with a special, mystical status (Flanagan & Holmes, 2000). It is an indiscriminate disease, and may affect any person at any time. In popular Western culture a diagnosis of cancer still equates to death in many circles

(Dein, 2004), and this fear has created a long-held taboo around discussing the disease, or even mentioning the word. This taboo is slowly changing in the Western world; however many people with cancer still feel the effects of the anxiety the word arouses - the stigmatisation of having cancer (Gordon, 1990; Stacey, 1997).

Patterson (1991) used the term 'cancerphobia' to describe the immense fear of the disease which exists in British and American culture. An attitude which, he claims, has endured since the late nineteenth century, despite the advances in medical science and efforts to 'bring it out into the open':

> "…Cancerphobia has been, and remains, a haunting reminder on both sides of the Atlantic of the continuing mystery of the dread disease, of the limitations of modern medicine, and of the certainty of human mortality." (Patterson, 1991, p149)

While the disease itself is undoubtedly more 'talked about' than in the first half of the twentieth century, public dread of it continues (Patterson, 1991), and its status as the most dreaded of diseases can cause additional harm to patients' social and interpersonal relations (Flanagan & Holmes, 2000).

The language of cancer is laden with metaphors, and these add a layer of meaning beyond the factual, and reflect how cancer is perceived in society. In her seminal (1978) publication Sontag drew parallels with tuberculosis in describing cancer as the modern dread disease, and delineated the militarised conception of cancer as a pernicious and invasive 'enemy', patients being required to 'fight' or 'battle' the disease, with aggressive treatments designed to 'kill' the cancer, yet destroying healthy parts of the person too. The use of such metaphors, Sontag argues, serves only to elevate cancer to

an “evil, invincible predator” (Sontag, 1978, p7) rather than just a disease, and metaphorical language thereby reinforces the myths and stigma surrounding, and popular fear of, cancer (Sontag, 1978; Penson et al, 2004). Stacey (1997) likens the cultural anxiety around the word ‘cancer’ itself and the proliferation of metaphors and euphemisms for the disease to her experience as a lesbian, a word similarly avoided and purged from conversation.

Public willingness to talk about cancer is increasing however, and there is also greater public awareness of the disease in modern times (Patterson, 1991). For head and neck cancer patients this may bring additional difficulties. As reported by patients with lung cancer (Chapple et al, 2004) the stigma and shame of having what is often regarded as a ‘self-inflicted’ illness due to widespread understanding of its link with smoking (Dein, 2004) may also colour HNC patients’ experiences. Smokers who develop oral cancer for example, may not only blame themselves, but fear or perceive others to be blaming them. These feelings, fear of negative reactions and uncertainty about how to tell people, and a desire not to be viewed differently – as a cancer patient – may conspire to produce isolation and social withdrawal (Wells, 2006).

In this climate, where cancer can still be experienced as a stigmatising condition, those HNC patients who have obvious functional impairments, and/or visible disfigurement, may feel the weight of this stigma even more. Visible physical imperfections, described as “the last bastion of discrimination” in beauty and image-obsessed Western culture (McGrouther, 1997), are stigmatising regardless of the cause, and these patients are literally marked out as different in terms of both their appearance, and the cancer.

2.6 THE PSYCHOSOCIAL IMPACT OF HEAD AND NECK CANCER

In a discussion of the psychological and social needs of people living with cancer, Holland & Reznik (2005), use 'psychosocial impact' to describe the psychological, social and spiritual distress experienced following a traumatic experience such as cancer. The authors advocate psychosocial care as a priority for individuals with resultant physical impairments which impact on their life and psychological functioning, and for those with resulting psychological problems or psychiatric disorders detrimental to quality of life. People living with and recovering from head and neck cancer frequently fall into both of these categories.

The radical treatments outlined previously often result in significant functional impairments, and because of this much of the literature pertinent to the impact of head and neck cancer is in the form of quality-of-life (QoL) studies. The remainder of this chapter will focus on the psychological and social impact of HNC as depicted in the quantitative and QoL literature. Research based on qualitative methods, and what this can reveal about the experience of head and neck cancer, is addressed in the meta-synthesis in Chapter 6.

2.6.1 OVERVIEW OF QUALITY-OF-LIFE RESEARCH

In respect of head and neck cancers, where both disease and treatments can produce severe personal and social consequences, quality of life is an important clinical consideration. Indeed improving quality of life, and social and psychological well-being are probably the greatest challenges in care, until significant breakthroughs in reducing the impairments imposed by treatments, and increasing survival rates, are achieved (Owen et al, 2001). With this aim in mind, the quality of life literature is vast. The recent emphasis on active patient participation in treatment decision-making demands that clinicians are able to convey the precise nature of risks from different treatments, both in

terms of short-term side effects and how it will impact on functional aspects of daily living in the long term (NICE, 2004). Quality of life studies seek to provide clinicians with such information.

A wealth of quantitative tools have been developed to provide standardised measurements of quality of life, which assess functioning in several aspects of life – physical, emotional, and social for example. Some have been devised specifically for head and neck cancer patients, and some include head and neck cancer-specific components. Global quality of life may be affected by numerous factors independent of the disease; for example marital or economic status, which are outwith the scope of potential clinical intervention. Therefore assessment of the more specific 'health-related quality of life' (HRQoL) – pertaining specifically to the impact of the disease and treatments on patients' overall well-being – has largely supplanted that of global or holistic quality of life (Murphy et al, 2007). Those quality of life measures particular to the head and neck cancer population are listed in Table 2. Excluded are instruments which are restricted to assessing the effect of only one particular disease or treatment feature on functioning/quality of life - such as voice quality or obturator functioning (Llewellyn-Thomas et al, 1984; Kornblith et al, 1996). Of special note are the EORTC and UW-QOL instruments, recently identified as most broadly used in the research setting with these patients (Rogers, Ahad & Murphy, 2007).

Table 2 - HNC QoL measures (adapted from De Boer et al, 1999; Murphy et al 2007)

	Measure	**Abbreviation**
1	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Head and Neck 37 (Bjordal et al, 1994)	EORTC QLQ-H&N37
2	Head and Neck Radiotherapy Questionnaire (Browman et al, 1993)	HNRQ

3	Functional Assessment of Cancer Therapy – Head and Neck Scale (Cella, Tulski & Bonomi, 1990)	FACT-HN
4	Function, Symptoms and Perception of Wellness Evaluation (Skeel, 1989)	FSPE
5	University of Washington Quality of Life Questionnaire (Hassan & Weymuller, 1993)	UW-QOL
6	Rotterdam Symptom Check List-Head and Neck, (De Haes, van Knippenberg & Neijt, 1990)	RSCL-H&N
7	Quality of Life Radiation Therapy Instrument Head and Neck Module (Trotti et al, 1998)	QOL-RTI/ H&N
8	Late Side Effects on Daily Life Scale (Jensen et al, 1994)	-
9	Oral and Pharyngeal Nursing Care Questionnaire (Langius & Lind, 1995)	OPNCQ
10	Performance Status Scale- Head and Neck (List, Ritter-Sterr & Lansky, 1990)	PSS-HN
11	University of Liverpool Questionnaire for head and neck cancer (Young et al, 1998)	-
12	University of Michigan Head and Neck Quality of Life Instrument (Terell et al, 2005)	HNQOL
13	QoL instrument pertinent to HNSCC patients (Mathias, Smith & Gonzalez, 1988)	-
14	Test series for functional evaluation of oral cavity cancer (Teichgraeber, Bowman & Goepfert, 1985)	-
15	Vanderbilt Head and Neck Symptom Survey (Murphy et al, 2002)	VHNSS

Studies have endeavoured to link psychological factors, demographic variables, and clinical variables to quality of life, and there are inconsistent results in many areas as to the importance of these factors. Beginning with a brief overview of the main physical/functional difficulties identified in the literature, this section will go on to describe some of the prominent psychosocial issues in head and neck cancer – rates of psychological morbidity, the importance of social support, fear of recurrence, impact on sexuality, and facial disfigurement.

2.6.2 PHYSICAL FUNCTIONING

The prior section on treatments highlighted a range of impairments to physical functioning which may be produced by the radical treatments for head and neck cancer. Recent reviews of the quality of life literature concur that patient scores tend to decline to their lowest point 3 months post-treatment, then steadily improve to approaching pre-treatment levels by 12 months (Murphy et al, 2007; Eades, Chasen, & Bhargava, 2009). The main areas of functioning disrupted amongst these patients are eating and speaking, and individual studies indicate these impairments to be of greatest concern to patients, and resolving them of great importance (Murphy et al, 2007). Overall dysfunction may be the result of a single side effect, for example radiation-induced dry mouth is sufficient to compromise the ability to eat, or the product of myriad conditions evoked from combined treatments – dryness conspiring with other oral side effects, and pain and reduced manoeuvrability of the tongue due to surgery for instance. Eades, Chasen & Bhargava (2009) cite restricted movement, pain, and fatigue as the other major physical impairments to quality of life.

The relationship between dysfunction and quality of life scores is not straightforward however, for example functional difficulties may persist long after treatment yet not impede improving perceptions of life quality (Murphy et al, 2007). This phenomenon points to a complex array of factors responsible for influencing perceived quality of life. It is not determined solely by the observable or measurable impact of the disease/ treatments, but by how this interacts with the individual's personal characteristics, beliefs, and expectations (Sayed et al, 2009). This subjectivity is increasingly paid heed by quality of life researchers, and is touched upon at the close of this chapter.

2.6.3 PSYCHOLOGICAL MORBIDITY

The proportion of head and neck cancer patients who experience significant psychological morbidity varies in the literature. Terrell et al (2004) claimed almost half of head and neck cancer patients in their sample tested positively for depression. Other studies have reported the rate of major depression – as defined by the 'Diagnostic and Statistical Manual of Mental Disorders' (DSM-IV) (American Psychiatric Association, 1994) – to be as prevalent as affecting between 20-30% of HNC patients (Kugaya et al, 2000; Katz et al, 2004; McCaffrey et al, 2007), though these apparently consistent studies are limited by their use of small sample sizes (e.g. just 23 patients as in McCaffrey et al, 2007). Rates of approximately one-third experiencing clinically relevant depression at mild or moderate levels are perhaps more credible, as cited in a recent study of HNC patients undergoing radiotherapy, where nearly 20% exhibited mild, and nearly 15% moderate, depressive symptoms (Sehlen et al, 2003).

Precise numbers may be difficult to determine, but most studies indicate prevalence of clinical conditions – as classified by the DSM IV – such as distress, anxiety and depression at levels above those found in the general population (Edwards & Jones, 1999). Further, it has even been suggested that HNC patients may experience higher levels of psychiatric morbidity compared to other cancer groups. This is partly due to the demographics of the population which correlate with higher levels of depression, and because patients may blame themselves for their cancer (Malcrane, Compas, & Howell, 1995). Attributing the cancer to their own alcohol drinking and/or smoking, patients are vulnerable to guilt, self-reproach, and even feelings that they deserve to have cancer (Gritz, 2000).

Much recent research has investigated factors which may be predictive of psychiatric morbidity with the aim of identifying sub-groups of head and neck cancer patients for

whom interventions should be targeted. For example demographic variables such as younger age; disease/treatment factors like shorter time since diagnosis (Hutton & Williams, 2001) or stage of radiotherapy treatment (Sehlen et al, 2003); and behavioural or lifestyle factors such as previous or current smoking (Humphris & Rogers, 2004) have all been associated with depression or anxiety.

The likelihood is that psychological morbidity in the form of distress, anxiety or depression results from the convergence of a complex combination of factors. The typical characteristics of HNC patients may partially explain their high QoL- related morbidity. This population are more likely to smoke tobacco, have high levels of alcohol consumption, and experience depressive symptoms and disorders, than the general population (Edwards & Jones, 1999). Duffy et al (2002) cited a strong negative association between depressive symptoms and all aspects of quality of life, and concluded that HNC patients who smoked, drank alcohol, and had depressive symptoms experienced a significantly lower quality of life. Thus quality of life scores may be likely to be lower in this group as a greater proportion of them possess these characteristics than the general population/other cancer populations.

2.6.4 THE IMPORTANCE OF SOCIAL SUPPORT

Many head and neck cancer patients come from socially deprived backgrounds, and a number have alcohol problems extending to addiction – circumstances not conducive to a wealth of social support. Social support refers to support proffered by others be they partners, friends, neighbours or other family members. Krishnasamy (1996) identifies three different kinds of social support:

1. Instrumental support – providing help of a material or practical nature, for example transport to and from hospital for appointments/treatment.

2. Informational support – providing information and advice, and assistance in tackling problems.
3. Emotional support – conveyance of positive affect towards the person, non-judgemental understanding, empathy, affection, and concern for the other's feelings.

The value of social support has been borne out by studies comparing patients living alone to those with families. For example Rozniatowski et al (2005) found that the majority of HNC patients living alone had delayed seeking medical attention – nearly two-thirds for over a month, and two-fifths for more than three months. The authors conclude that partner and family relationships play an important role in the patient's ability to acknowledge the seriousness of symptoms and the necessity to consult.

There is evidence that patients with head and neck cancer cope with their disease and the impact of treatments better when they have a good support network. Social support appears to play a protective role against psychological distress (Kugaya et al, 2000), and developing depressive symptoms (Humphris & Ozakinci, 2006), in the immediate post-diagnosis period. While for women, social support can make a significant positive difference when coming to terms with a disfigurement after surgery for head and neck cancer (Katz et al, 2003).

Perhaps most provocatively, recent research has demonstrated an association between social support and cancer survival. Pinquart & Duberstein (2010) integrated the findings of 87 studies on this topic, and cite a higher risk of mortality for cancer patients who are unmarried, have lower perceived support, and have a smaller (numerical) support network, though further research is required to elucidate the mechanisms responsible for these associations. Such an association has also been reported specific to head and neck

cancer, with men who live alone significantly disadvantaged in terms of survival independent of disease and demographic variables (Konski et al, 2006).

The literature surrounding the impact of social support on quality of life is inconsistent. This in part is due to different conceptualisations of social support and use of different instruments of measurement. It is likely that the patient's perception of social support, and how closely available support matches their needs, is more important than amount of support available however (Llewellyn, McGurk, & Weinman, 2005). Indeed, in a study of 394 head and neck cancer patients, Karnell et al (2007) found significant correlations between higher post-treatment levels of perceived social support and several aspects of health-related quality of life, including better scores concerning speech, facial aesthetics, social disruption, mental well-being, and fewer depressive symptoms.

2.6.5 FEARS OF RECURRENCE POST-TREATMENT

Fears of the cancer recurring after completion of treatment are not uncommon among people with cancer. Patients are usually followed-up for a period of five years post-treatment, and the main aim of follow-up appointments is to monitor for signs of recurrent disease. This period is often one where patients are hyper-vigilant in their monitoring of unusual bodily sensations and frequently interpret anything unusual as recurrence, though evidence suggests that these fears are often not shared with clinicians, and so the patient may have to cope with the fear and uncertainty alone (Humphris & Ozakinci, 2006).

Fears of recurrence have also been shown to be persistent over time. Humphris et al (2003), investigated recurrence fears and psychiatric morbidity among two groups of HNC patients –one from diagnosis through 7 months post-treatment, the other from at least one year post-treatment over two years. Among the first group recurrence fears

dominated and did not decrease significantly between 3 and 7 months after initial treatment. A lack of a meaningful reduction over time was also observed in the second group, indicating a stubborn persistence to fears of recurrence. Additionally there was an association between these fears and generalised anxiety.

2.6.6 SEXUALITY

Although the impact of head and neck cancer on sex life is addressed to a degree in studies relating to quality of life and body image, there is little specific research into sexuality after treatment for HNC. The majority of sexuality-specific research concerns cancer in general, and more obviously related cancers such as breast, testicular, prostate, cervical, and other gynaecological cancers. This is perhaps an important oversight, as psychological difficulties, impaired bodily functioning and body image, and altered physical appearance are factors known to negatively impact on sexuality (Holland & Reznik, 2005), and these concerns are so frequently noted among HNC patients. Indeed amongst this patient group body image has been significantly linked to problems with intimacy post-treatment (Low et al, 2009).

Poor sexual functioning has been indicated in quality of life research, and in the limited number of focussed studies. While physical functioning tends to improve gradually in the months following treatment completion, large sample studies have shown a decline or deterioration in sexual functioning towards the end of the first year post-treatment (Gritz et al, 1999; Bjordal et al, 2001). The persistence of sexual difficulties amongst HNC patients has been indicated by a recent large-scale survey which found that approximately one third of patients suffered 'long term' problems (though this was assessed only by time since treatment at questionnaire completion, and would require longitudinal follow-up to establish a sustained period of difficulty) (Low et al, 2009).

Specific difficulties include loss of interest in sex, and problems becoming aroused and reaching orgasm (Monga et al, 1997; Low et al, 2009),

As per recurrence fears, it has been claimed that HNC patients' concerns over sexual difficulties and dysfunction may be overlooked in the clinical environment (Munro & Stafford, 2007). There appears to be a lack of routinely-provided information about sexual issues, a result of many factors including clinician and patient apprehension and uncertainty as to the appropriate time to impart such information (Katz, 2005). Thus in spite of research evidence indicating that sex is important to HNC patients, and that sexual concerns or the loss of sex drive produce distress, many HNC patients may have to cope with the fall-out in this aspect of their lives without much apparent support.

2.6.7 FACIAL DISFIGUREMENT

Living with visible disfigurement in a Western culture which places so much value on physical attractiveness can be extremely difficult to adapt to. Although increasingly the media is focussing on the masculine physique, imposing on men too impossible ideals of perfection, for women the cultural emphasis on beauty is even more ingrained.

Gender does appear to play an important role in how patients perceive themselves, and are perceived by others, following disfiguring surgery. Katz et al (2003) found significant gender differences in psychosocial adjustment in HNC patients who had undergone disfiguring surgery. Women reported more depressive symptoms, and lower 'life happiness'. Despite claiming to have lower levels of social support than men, where support was available, women derived greater benefit from it – it appeared to moderate the psychosocial impact of disfigurement. The different cultural standards of male and female beauty are also reflected by others' perceptions of disfigurement. For example one study found Head & Neck Oncology nurses generally rated female

patients as more disfigured than males after identical surgeries (Lockhart, 2000). Regardless of these differences however, both genders must deal with the significant personal and social consequences of facial disfigurement, and the disruption to body image.

'Body image' is defined by Dropkin (1999, p.309) as one's "perception of one's own bodily appearance, functions and sensations", and encompasses the associated emotions. The disfigurement and dysfunction which can result from surgery produces changes to one's perception of self, and often psychological difficulties (Rumsey et al, 2004; Katz et al, 2003). After head and neck cancer surgery, the assimilation of the subsequent disfigurement and dysfunctions into one's sense of self is termed 'body image reintegration'. In a small sample study of disfigured head and neck cancer patients, it was found that dysfunction was more readily assimilated into one's self image than disfigurement, and that achieving body image reintegration was characterised by three processes: alteration of one's existing body image, engagement in self-care activities and re-socialisation, and decreased levels of associated anxiety (Dropkin, 1999).

2.6.8 VALUE AND LIMITATIONS OF QUANTITATIVE AND QOL STUDIES

Research of the kind presented above enables the impact of head and neck cancer to be measured over the course of the disease and can identify which particular problems may require addressing at specific points across the trajectory. Quality of life scores tend to deteriorate significantly whilst undergoing treatment and as side effects reach their peak, but across most domains slow, gradual continuing improvement is observed once treatment is completed (Bjordal et al, 2001; Ledeboer et al, 2005). Large-scale quantitative studies such as these enable the identification of rehabilitation needs, and also facilitate comparison of the impairments faced by different sub-sections of patients, for example males and females, or those treated with alternate modes of surgery.

However, an important consideration regarding the tools used to measure QoL was raised by Gritz et al (1999), in that they do not assess individual factors such as motivation or expectations, and how these may impact on perceived quality of life. Quality of life tools have also, thus far, paid insufficient attention to the possibility of response-shift, whereby patients ratings of quality of life are relative to changes in their life overall, and the clinical importance of response-shift has yet to be determined (Schwartz et al, 2006; Barclay-Goddard, Epstein, & Mayo, 2009). Further, De Boer et al (1999) in their review criticised the lack of consistency in terms of domains considered relevant – at that time only one measure assessed body image and self image for example. In the intervening period this has changed, with additional domains being tested empirically for inclusion in quality of life measures on a regular basis – for example domains for scoring mood and anxiety have been incorporated into the UW-QOL (Rogers et al, 2002). In addition there is an increasing interest in more individualised measures such as the Patient-Generated Index (PGI) to investigate how patients perceive their quality of life and which areas are most important to them, in respect of the fact that quality of life is highly subjective (Ruta et al, 1994; Sayed et al 2009).

Individualised measures may be more successful in capturing the sense of quality of life, rather than the quality of life as defined by pre-set measures (Llewellyn, McGurk & Weinman, 2006). For example, whilst poorer functioning scores on some domains may be the root of psychological distress in some patients, others may not place the same value on certain types of functioning, and therefore the same disability may be of less concern to them. The use of individualised measures may go some way towards eliciting the more subjective impact of head and neck cancer on patients' lives, however it is qualitative research which really excels at this, and which can fill in those gaps in the

understanding of patients' experiences that the vast quality of life literature cannot. As previously stated, the qualitative literature will be addressed subsequently, in Chapter 6.

2.7 CHAPTER SUMMARY

This chapter has demonstrated the devastating effect that head and neck cancer can have on patients' physical, psychological, and social well-being. The acute impact of treatments is severe, and may induce long-term deficits to quality of life. Physical functioning declines as treatment progresses and continues to do so in the first few months following completion. Impairments to the ability to eat and speak are cited as the most dominant problems, and those which cause most concern to patients; while disfiguring surgery can also produce permanent changes in self-image. The psychological impact of the disease is also substantial – the incidence of anxiety and depression tends to exceed that of the general population, and fears of recurrence are common. The physical and psychological ramifications of HNC may also be detrimental to patients' ability or inclination to interact socially. A high proportion of HNC patients are from socially deprived backgrounds, and often continue to engage in behaviours more frequent in low socioeconomic groups, such as smoking, which can be greatly detrimental to their survival chances. In this context, head and neck cancer patients in particular may benefit from interventions to promote psychological well-being, and address harmful behaviours to maximise both quality and quantity of life.

The impact of HNC on the individual's quality of life is mediated by demographic, social, and psychological factors, as well as the physical changes brought on by the disease and treatments. Patients' illness beliefs have also been identified as impacting on quality of life, and are known to be important determinants over psychological, behavioural, and other health outcomes. This is reflected in the significant proportion of the literature which has linked various quality-of-life deficits to specific illness perceptions. The

following chapter outlines the importance of patients' beliefs in terms of their relationship to psychological and behavioural outcomes of disease. If such outcomes are to be improved for HNC patients, it is important to understand how they perceive the cancer, though as indicated in the penultimate section of this chapter, there are limitations to how beliefs are currently measured. Chapter 3 will go on to demonstrate how patients' comprehensions of their illness may include a visual element – that patients may generate a mental image of their disease which embodies their beliefs about it. Thus far research into the role of such images in patients' illness perceptions has received little attention, and the subsequent chapter will illustrate the potential importance of addressing this.

3 EXPLICATING THE IMPORTANCE OF ILLNESS BELIEFS, PATIENTS' MENTAL IMAGES OF THEIR DISEASE, AND EXISTING APPROACHES TO ACCESSING THESE

The purpose of this chapter is to outline the theoretical framework underpinning the thesis. Primarily the thesis is grounded in Leventhal's self-regulation model which characterises the psychological experience of illness and emphasises the importance of patients' illness beliefs (or 'illness representations') in influencing their experiences of disease, illness-related behaviour, and health outcomes. Empirical support for this theory is extensive, and relevant research carried out on this basis is presented. The second function of Chapter 3 is to present recent research which has suggested that patients' illness beliefs may be embodied in visual form, in mental images of their disease, and that beliefs embedded in images may also powerfully affect patients' experiences, behaviour, and outcomes. The concept of 'mental images' is explained fully, and it is argued that a patient's 'knowledge' of their illness can be visual as well as words-based or verbal in nature, and that the employment of visual methods to access illness beliefs may provide further insight into patients' understandings and experiences of disease. Studies which have explored the communicative value of patients' drawings, and the small but growing body of research which has attempted to examine patients' beliefs by eliciting their internal mental images of their disease, are then detailed; and existing approaches to externalising and analysing patients' mental images delineated.

3.1 THEORETICAL BACKGROUND: LEVENTHAL'S SELF-REGULATION MODEL

The theoretical backdrop to this thesis is Howard Leventhal's self-regulation model (SRM) (Leventhal, Meyer & Nerenz, 1980). Also known as the 'common-sense model' or

'parallel processing model', the SRM is an attempt to characterise the psychological experience of illness, and it is within this theoretical framework that the thesis' focus on mental images must be understood. From a health psychology perspective, Leventhal proposed the SRM as a way of understanding the relationship between the underlying psychological processes which occur when a person encounters a threat to their health, and their illness-related behaviour. The basic assumption of the SRM is that people strive to maintain a sense of normality, or to 'regulate' the self. Any disturbance to the equilibrium in the form of a perceived health threat is met with attempts to restore it via the interplay of three conscious processes: interpretation, coping, and appraisal (Leventhal, Meyer & Nerenz, 1980).

(i) Interpretation of the threat and construction of a mental representation ('illness representation') which comprises both cognitive and emotional representations

(ii) Identification and implementation of coping procedures to manage the problem

(iii) Appraisal of the success or failure of the coping strategies/procedures employed

As a threat to health is recognised, the individual interprets a range of information about their symptoms or diagnosis in order to 'make sense' of it. There are three main sources of information drawn upon: lay knowledge of illness (e.g. widely held or prevailing knowledge), information imparted by perceived knowledgeable parties (e.g. doctor), and the person's somatic experience of the illness (symptoms) (Leventhal, Nerenz, & Steele (1984). The mental output of this interpretation is the construction of a mental representation of the health problem – an illness representation. This is composed of simultaneously-generated cognitive and emotional representations of the illness. The cognitive representation incorporates the individual's common-sense beliefs along five

dimensions: the identity of the illness, perceived cause, anticipated consequences, timeline in terms of onset and expected duration, and prospects of cure or controlling the illness (further detail on these dimensions is provided in Table 3). The accompanying emotional representation encompasses the emotional response to the illness – and may for example include fear, anxiety or shame.

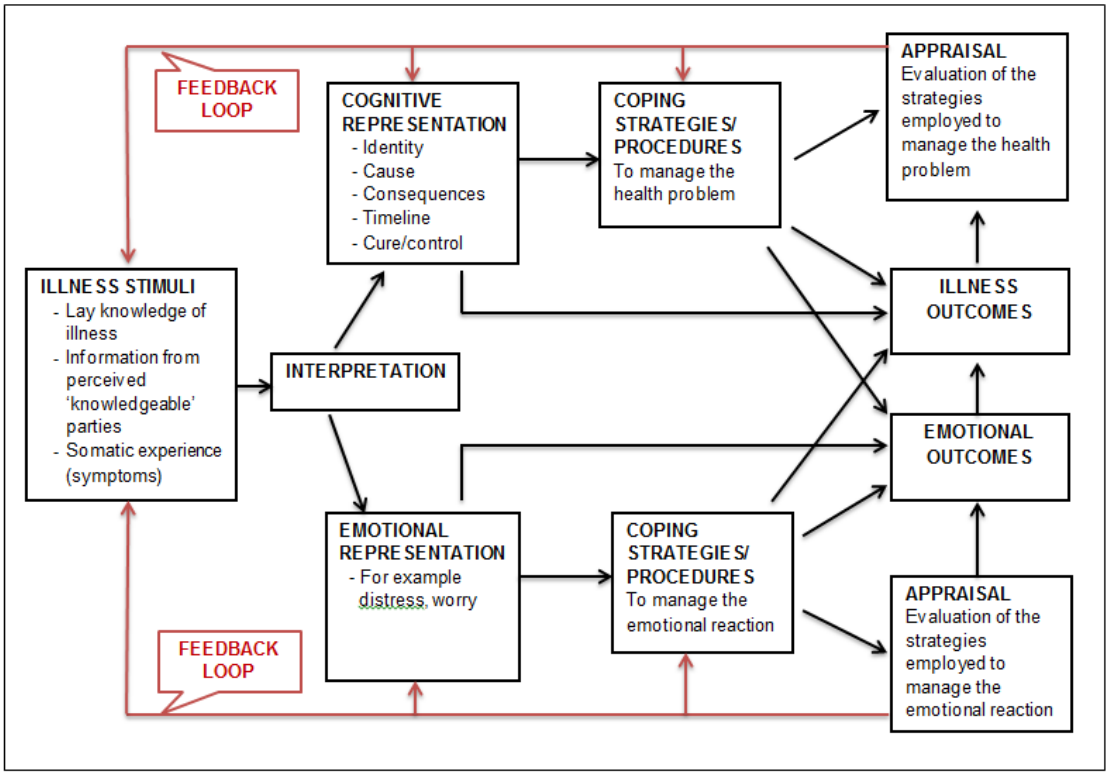
Table 3 – The five dimensions of the cognitive representation of illness

Dimension	**May include beliefs about…**
Identity	Illness label – the name of the condition/diagnosis Symptoms – which unusual sensations are due to the condition
Cause	Perceived cause of the illness/symptoms
Consequences	Physical impact of the illness Social impact – i.e. 'I'll have to take time off work' Likely outcome – i.e. return to normal, death
Timeline	Onset – when the symptoms began Predicted duration – may be acute, cyclical, or chronic
Cure/Control	Likelihood of the illness being cured or controlled Actions/treatments required to alleviate the illness May include beliefs about the level of internal (personal) control as well as external control

In response to their mental representation of the illness, the individual then identifies and implements procedures in an attempt to re-establish their health equilibrium. An individual's behaviour in relation to the health threat is therefore is considered to be logical within the context of their illness representation, regardless of whether this is medically valid (Meyer, Leventhal & Gutmann, 1985). The cognitive representation provides the basis for strategies to manage the health problem - for example self-medicating or seeking medical help; while the emotional representation requires the employment of procedures to manage the individual's emotional reaction to the problem. The efficacy of these strategies is then monitored continually, and their perceived success or failure is the subject of 'feedback' from which the illness representation may be

modified, and further coping procedures adopted, until the problem is resolved (Leventhal, Meyer & Nerenz, 1980). In this manner illness representations are dynamic rather than static or fixed mental constructs. Figure 2 below provides an overview of the self-regulation model illustrating the dynamic and interactive nature of this process.

Figure 2 - Leventhal's self-regulation model (Adapted from Hagger & Orbell, 2003, p144)



The central psychological component of the self-regulation model then is the concept of the 'illness representation' – a set of beliefs about the nature of the health threat (cognitive representation), and the emotional response to it (emotional representation) – which guides the procedures or behaviours employed to manage the threat to health (Leventhal, Meyer & Nerenz, 1980). For the purpose of this thesis the self-regulation model, in particular the concept of illness representations, provides a framework within which to consider the potential role of mental images in the psychological experience of illness. The terminology used throughout this thesis is drawn primarily from this theoretical framework, and will be applied in a manner consistent with the definitions outlined in this

section. A brief definition of these terms is provided in Table 4 below (see also the glossary)

Table 4 - Definition of terms related to the self-regulation model

Illness representation	The patient's mental representation or understanding of their illness. This comprises both a cognitive representation and an emotional representation.
Cognitive representation	Beliefs about the illness. May include beliefs about the identity, cause, consequences, timeline, and curability/ controllability.
Emotional representation	Feelings about the illness.
Illness beliefs / illness perceptions	Specific ideas about the illness as per the five domains proposed by Leventhal (components of the cognitive representation)

3.1.1 KLEINMAN'S EXPLANATORY MODELS

Although this thesis uses the SRM as its theoretical framework, some of the research in this field is based on an alternative theory, which should be briefly mentioned. This alternative theoretical concept in fact mirrors Leventhal's basic notion of illness representations, but has a somewhat different foundation. Developed from a medical anthropology perspective, Arthur Kleinman's concept of explanatory models is also an attempt to characterise how people make sense of and respond to illness. Kleinman's theory differs from Leventhal's in its scope – he studied cultural and physician/healer explanatory models in addition to those of patients. Explanatory models can be said to exist on two basic levels; on a cultural level and an individual one. Culture-wide explanatory models determine how health and illness are conceptualised and understood, and how healthcare systems are constructed within a particular society. For example, the Western explanatory model is mechanically-driven, the body akin to a car engine requiring the intermittent attention of a mechanic, in the form of a health

professional, to repair faults (Hallenbeck & Weissman, 2000). Within these overarching cultural explanatory models, individuals then formulate more refined, specific explanatory models in response to particular ailments, and these govern how they identify and act upon specific symptoms (Kleinman, 1980). Such individual-level explanatory models encompass beliefs about cause, mode of onset and symptoms, changes in bodily functioning (pathophysiology), and appropriate treatments, and are based on their culturally determined perceptions of symptoms and illness meaning (Kleinman, 1980).

Though the underpinning ideologies of illness representations and explanatory models differ, they express overtly similar ideas about the cognitive framework by which individuals make sense of illness, and the dimensions of these. Both also propose that the behaviour subsequently adopted is influenced primarily by these rationalisations. Therefore, the research presented in this chapter will include studies which have utilised either theory, though Leventhal's model remains the primary theoretical foundation for this thesis and the empirical work reported in subsequent chapters will be related specifically to his concept of illness representations. The following section will outline the factors which have been identified as influencing the construction of illness beliefs, and will demonstrate the value of Leventhal and Kleinman's theories by providing an overview of the substantial body of research which supports a link between beliefs and patients' psychological well-being, health behaviour, and outcomes.

3.1.2 THE DIVERSITY OF ILLNESS REPRESENTATIONS AND EXPLANATORY MODELS

Kleinman's theory was born of anthropological studies of different healthcare systems in Eastern cultures, and he emphasised the role of culture in determining lay health beliefs (Kleinman, 1980). Research has contrasted explanatory models of illness across different

countries (for example Dein, 2004), and demonstrated within-culture variations according to the sub-groups to which people belong. For example, Karanz (2005) studied two groups of women from different sub-cultures in New York - interviewing affluent white Americans, and working class South Asian immigrants about their understandings of depression. The former conceptualised depression as an illness, congruent with the Western, medicalised, psychiatric view; while the latter emphasised social and relational factors – depression as an emotional response rather than a medical condition.

Within the broader societal context, illness beliefs have also been found to vary according to individual factors such as gender, socioeconomic status and race. In the case of gender, women may exhibit lower perceived susceptibility to heart disease (Banks, 2008), may be less likely to attribute their initial symptoms to a cardiac problem (Martin et al, 2004), and tend to differ from men in their beliefs about the cause of the heart attack (King, 2002). The impact of socioeconomic status on health is well documented (Marmot et al, 1997), and variance in illness beliefs, and consequently behaviours, is one factor in this equation – people from lower socioeconomic groups holding stronger beliefs in 'chance' as a causal factor in disease for example (Wardle & Steptoe, 2003).

In cultures with a mixed racial population, comparative sample studies have also reported statistically significant differences in illness beliefs according to race or ethnicity, in areas such as depression causation (Payne, 2009), and the effectiveness of treatments for mental illnesses (Anglin, Alberti, Link & Phelan, 2008). The conceptualisation of symptoms as a medical condition may also vary, for example one recent study found Chinese and Hispanic caregivers were more likely to perceive Alzheimer's disease to be a normal part of the ageing process, rather than a distinct illness which is not necessarily inevitable (Gray et al, 2009).

3.2 THE POWER AND SIGNIFICANCE OF ILLNESS BELIEFS

The importance of understanding illness representations/explanatory models has been borne out by a substantial body of research which indicates that patients' psychological well-being, behaviours, and – by virtue of these – overall health outcomes, are influenced by their understanding of their condition. The following section provides an overview of the kinds of issues investigated in relation to illness beliefs among different clinical populations.

3.2.1 PSYCHOLOGICAL WELL-BEING

A sizeable body of research has measured psychological distress alongside illness perceptions. Quantitative assessments of distress are common inclusions to quality of life studies and an important outcome measure. The incidence of psychiatric morbidity - depression and anxiety – has been linked to specific illness beliefs in a range of clinical populations. In particular, the perception that the illness will have serious consequences has been strongly associated with subsequent psychological distress (Fortune et al, 2002; Hagger & Orbell, 2003; Evans & Norman, 2009).

Timeline beliefs – the anticipated duration of the condition, whether it is conceptualised as acute, chronic, or cyclical – have been similarly associated with psychological distress post-treatment. For example a chronic or cyclical timeline construct has been found to predict depression, anxiety and fear of recurrence among breast cancer patients, independent of clinical variables such as disease stage (Rabin, Leventhal, & Goodin, 2004). A larger sample study of 269 heart attack (myocardial infarction or 'MI') patients also reported an independent predictive value to timeline beliefs. Assessed at hospital admission, a 2.7-fold increase in new depressive episodes over the subsequent 12 months was observed amongst patients who believed their heart disease would last a long time (Dickens et al, 2008).

Findings such as these suggest that the emotional consequences of illness are determined by the specific meaning it has for the individual, rather than clinical or disease factors alone.

3.2.2 BEHAVIOUR

The influence of patient behaviours on the disease course has been documented with particular reference to adherence to treatment regimens and engagement in self-care activities. If, as Leventhal and Kleinman contend, people act in a way which is logical in the context of their illness perceptions, much patient behaviour may be explained by understanding their underlying beliefs, and a substantial body of research has explored this.

Specific illness perceptions and combinations of beliefs have been identified as influencing adherence to health professional recommendations in both patient and non-patient groups. For example Mann et al (2009) found non-chronic timeline beliefs and anxieties about medications among diabetes patients to be significant predictors of poor medication adherence. Representations of illness in non-patient populations become salient when preventative behaviours are considered. Smoking, poor diet, and a lack of regular exercise have all been associated with fatalistic beliefs about cancer causation (Niederdeppe & Gurmankin Levy, 2007). Low perceived personal control over the development of diseases like this provides no impetus for adopting a healthier lifestyle.

A strong belief in the potential to cure or control the illness has been cited as a significant factor in attendance at outpatient appointments in a variety of clinical populations, including psoriasis patients (Scharloo et al, 2000), and MI patients (Petrie et al, 1996). Isolated cure/control beliefs are not the sole factor in clinic attendance however, for example a recent systematic review of cardiac rehabilitation attendance

indicated that the coherence of the illness representation (the extent to which patients feel they have a clear understanding of their MI), perceived serious consequences, and a higher number of perceived symptoms were also important determinants (French, Cooper, & Weinman, 2006).

Findings such as these suggest patient behaviours are the product of the interplay of multiple illness beliefs. The influences on overall health outcomes are even more complex, with biological factors mediated by belief-driven behaviours, as will now be briefly outlined.

3.2.3 HEALTH OUTCOMES

Illness beliefs may influence health outcomes via the effects of psychological distress on physical health, and the consequences of patient behaviours, though the precise relationships between factors are difficult to determine. In the former instance, for example, distress in the form of excessive worrying was found to be the chief predictive factor of the time taken for photo-chemotherapy treatment to clear psoriasis (Richards et al, 2004).

One kind of measureable disease outcome is the degree of disability which results. Cross-sectional studies have cited illness perceptions as significantly related to extent of disability in chronic conditions such as psoriasis (Fortune et al, 2002), and rheumatoid arthritis (Carlisle et al, 2005), independent of disease severity. Similar correlations have also been found in some of the quality of life literature in relation to other types of functioning, for example Scharloo et al (2005) reported a significant association between illness beliefs and quality of life on physical, role, emotional, cognitive, social functioning, and global health subscales among head and neck cancer patients. Even more compelling is the evidence from longitudinal research which indicates that baseline

illness beliefs may have a predictive value in terms of outcomes. Petrie et al (1996) found that time taken to return to work following a myocardial infarction (MI) was independently predicted by perceptions of consequences and timeline beliefs, irrespective of clinical variables – a finding replicated subsequently by Broadbent et al (2004).

3.3 EXAMINING ILLNESS PERCEPTIONS IN A CANCER CONTEXT

The bearing of illness beliefs on behaviour means it has particular applicability to chronic, debilitating conditions which require the patient to perform self-management activities. The research discussed herein has referred to a multitude of such conditions, including rheumatoid arthritis, fibromyalgia, diabetes, and heart disease. The literature also pays great heed to how psychiatric patients and their relatives conceive disorders such as schizophrenia and bipolar disorder, which require extremely careful medication control (Das et al, 2006; Kuipers et al, 2007; Hou, Cleak, & Peveler, 2010).

Research explicitly focussed on patients' perceptions of their cancer has been limited. A number of studies have explored cancer patients' illness beliefs in the context of other psychological variables, without employing standardised measures like the Illness Perceptions Questionnaire (IPQ), or being specifically tied to Leventhal's model (Kaptein et al, 2003). Primarily, existing research has attempted to link specific illness perceptions to psychological outcomes like distress post-treatment (Millar et al, 2005; Traeger et al, 2009), adjustment to cancer (Gould, Brown, & Bramwell, 2010; Lichtenstein Jorgensen et al, 2009), symptom experience (Paddison et al, 2009), and aspects of quality of life (Scharloo et al, 2005; Llewellyn, McGurk, & Weinman, 2006), amongst discrete cancer populations, including breast, gynaecological, colorectal, prostate, and head/neck cancers.

The illness representations of potential cancer patients have also been examined. In particular, attendance at cancer screening has been a focus of attention in an effort to link particular beliefs to non-attendance behaviour (Cameron, 1997). Groups identified to be at risk following screening have also been studied in relation to coping and psychological distress, for example female carriers of breast or ovarian cancer genes (Claes et al, 2005; Shiloh et al, 2009), and patients who received an abnormal test result following colorectal cancer screening (Orbell et al, 2008).

3.4 THE VALUE OF ILLNESS BELIEFS RESEARCH – POTENTIAL FOR CHANGE

Studies like the kind presented above suggest illness beliefs can contribute independently to psychological morbidity, negative health behaviours, and poor outcomes in a diverse range of clinical conditions. It is the arguably pliable, changeable nature of such beliefs that is the key to the value of research in this area however, as the potential to modify patients' perceptions of their illness may lead to an improvement in disease outcomes.

Tackling misperceptions about the health risks associated with smoking is one focus of interventions developed with this aim in mind. As patients construct illness representations/explanatory models in a logical fashion, a level of coherence is required when assimilating information about risks. Put simply, specific risks must make sense to the patient. One example where coherence is understandably difficult – due to the dissociated nature of the body parts involved – is the link between smoking and cervical cancer. A study claiming to be the first attempting to increase illness coherence (Hall, Weinman, & Marteau, 2004) addressed this area with a leaflet-based intervention, and

achieved moderate success in raising perceived susceptibility to cervical cancer among female smokers - in turn linked to greater intentions to stop smoking.

Coherence is just one theoretical basis for illness belief interventions. Other studies have endeavoured to educate patients and instil more positive beliefs. A randomised trial of an intervention with MI patients aimed at addressing negative perceptions effectively modified timeline and cure/control beliefs, and benefitted the recovery of the intervention group in terms of fewer reported angina symptoms, increased attendance for rehabilitation, and speedier return to work (Petrie et al, 2002).

While intervention studies such as these affirm the changeable nature of illness perceptions, the persistence of original beliefs has also been observed. For example Das et al (2006) reported the selective resistance of explanatory models to change following a psycho-educational intervention with relatives of schizophrenia patients in India. Explanatory models of the intervention group were altered significantly in terms of a reduction in the number of non-biomedical causal models of psychosis, but at follow up many indigenous aspects of EMs remained, most particularly notions of appropriate treatments. This suggests certain illness beliefs may be more amenable to modification than others.

3.5 ACCESSING ILLNESS BELIEFS

Research examining patients' illness beliefs has primarily utilised oral or textual methods. Originally both Leventhal and Kleinman used interviews consisting of open-ended questions to elicit illness beliefs, but the popularity and wide applicability of their theories has driven the development of more objective standardised measurement tools. Such tools founded on Leventhal's model are strictly quantitative in nature. The first one developed was the 'Illness Perceptions Questionnaire' (IPQ) which was published in 1996

and provided a scoring system for the five dimensions of illness representations (see table 3, page 47) (Weinman et al, 1996). A revised version, the IPQ-R, was subsequently developed, expanded to include items to assess the emotional response to illness, and refined in some instances – delineating between personal and treatment control beliefs (Moss-Morris et al, 2002). The greater detail of the IPQ-R rendered the measure time-expensive to administer however, and a condensed one-page version of the questionnaire – the Brief IPQ – has since also been published (Broadbent et al, 2006).

Kleinman (1980) initially proposed eight basic open-ended questions for accessing patients' explanatory models. Researchers approaching illness beliefs from this standpoint have since elaborated on these questions and proposed more detailed, qualitatively-orientated interview schedules: the 'Explanatory Model of Illness Catalogue' (EMIC) (Weiss, 1997); the 'Short Explanatory Model Interview' (SEMI) (Lloyd et al, 1998); and the 'McGill Illness Narrative Interview' (MINI) (Groleau, Young, & Kirmayer, 2006). Each of these tools assesses the same dimensions of explanatory models, but the tools differ as to their explicit focus (Houtu, 2008). The most recent development in assessment tools is the 'Barts Explanatory Models Inventory' (BEMI), which comprises both quantitative and qualitative elements, though the validity of this in different cultural contexts is yet to be established (Rudell, Bhui, & Priebe, 2009).

3.5.1 IS KNOWLEDGE SOLELY WORDS-BASED?

Although these structured tools for measuring illness beliefs have been widely utilised and are well regarded in the literature, they rely on a purely word-based manner of expressing beliefs. However recent authors have embraced visual methods as drawings to explore patients' experiences of illness, and a growing body of research has suggested that patients may also visualise their disease, and that their perceptions of

their illness may be embodied in visual form, in mental images of the disease. Research in this area has produced some compelling findings indicative of a relationship between such images and illness beliefs, and has questioned the ability of oral and written assessments to access beliefs embedded in mental images. The notion that knowledge may be visual as well as verbal in nature forms the basis for this thesis, and the remainder of this chapter will demonstrate the potential value and importance of accessing patients' visual knowledge of their disease.

3.6 IMAGES AND EXPERIENCES OF ILLNESS

Illness beliefs are but one component of patients' overall experiences. The previous section showed how beliefs can influence the emotional impact of the disease, related behaviours, and by virtue of this, overall health outcomes. This section will begin by demonstrating the increasing use of visual methods to investigate experiences of illness, and go on to describe the utility of such methods in specifically accessing illness perceptions.

3.6.1 CHILDREN'S DRAWINGS AS A COMMUNICATIVE AID

Traditionally visual methods such as drawings have been employed mainly as a communicative aid with child patients. Recognition that children may have difficulty articulating their thoughts and feelings has led to a long tradition of interpreting their drawings, both spontaneous and guided, as indicators of underlying psychology. This trend continues in the realm of child mental health. In a recent survey of 158 clinical psychologists, 36% reported frequent use of informal or 'free' drawing with child clients, while a further 12% stated that they 'always' used free drawings. Such drawings are utilised as an 'informal aid to assessment', though the manner in which they are

interpreted and their subsequent bearing on the diagnosis of psychological conditions has yet to be clarified in the literature (Bekhit, Thomas, & Jolley, 2005).

The communicative value of drawings has also been explored in relation to the diagnosis of physical conditions such as migraines. Analysis of the presence or absence of features consistent with migraines (such as nausea/vomiting) in 226 children's drawings of 'what their headache felt like', accurately predicted migraine diagnosis in 87.1% cases (Stafstrom, Rostasy, & Minster, 2002). Distinctive differences in the attributes of children's headache drawings according to type of headache were also reported by Wojaczynska-Stanek et al (2008), though they reported correct health professional diagnosis in only approximately half of cases. These authors cited participating Professionals' comparative lack of knowledge about headache diagnostic criteria and the psychological analysis of drawings as a potential explanation for the poorer accuracy rate of their study, and maintained that child drawings can be a useful diagnostic aid. Other clinical uses of child art which have been explored include its value as a method of engaging with children in primary care settings (Stein, 2001), to assess anxiety in the context of dental appointments (Sheskin, Klein & Lowental, 1982), and in assisting health professionals in understanding children's anxiety and self-esteem issues prior to cosmetic surgery (Lukash, 2002).

The idea that drawings may convey information that children are unable to express effectively in words, has carried over into research into the experiences of child patients. For example children who have been confined to hospital for periods of time have been encouraged to relate their experiences of that environment pictorially (Sartain, Clarke, & Heyman, 2000; Pelander, Lehtonin, & Leino-Kilpi, 2007). Drawings have also been used to illuminate children's perceptions of their illnesses, and of themselves as sick children, in

serious conditions such as leukaemia (Massimo & Zarri, 2006), and epilepsy (Stafstrom & Havlena, 2003).

3.6.2 ADULTS' ART AS AN ALTERNATIVE METHOD OF COMMUNICATING ILLNESS EXPERIENCE

Increasingly artistic, visual mediums are also being used in research with adults as a way of communicating their experiences of illness (Harrison, 2002). Rather than overcoming difficulties in articulation, visual methods are being embraced with adults as an adjunct to other qualitative methods, yielding a different kind of data which can enhance patients' accounts of illness. In addition to drawings, other visual methods have also been employed to this end, for example 'photo elicitation' as a technique to explore experiences of hospitalisation (Radley & Taylor, 2003), cancer and its treatments (Oliffe & Bottorff, 2007; Frith & Harcourt, 2007). However the literature presented here will consist exclusively of studies which have incorporated patient-produced drawings, as this is the preferred visual method for assessing illness perceptions, which will be described later.

A key proponent of the use of patients' drawings to investigate illness experiences is Guillemin (2004b, p275), who incorporated drawings into a qualitative study of women's understandings and experiences of heart disease and advocated:

> "The drawing as a visual product is a visual record of how the drawer understands his or her condition at that particular place or time"

Patients' drawings revealed not only the individual's conception of their condition, but also reflected their experiences, and the meaning of the heart in the broader social and cultural context (Guillemin, 2004a).

Drawings elicited from adult patients tend to differ from children's in respect of their greater potential abstract or metaphorical capacity. Metaphorical images can express powerful feelings about several dimensions of illness experience. For example in a study of the subjective meanings of AIDS one patient described her image of it as a 'crying skeleton', expressing her feelings about impending death (Anderson & Spencer, 2002), while another sample of HIV patients reflected the social exclusion and stigma of an AIDS diagnosis in their drawings (Scott, 2009).

The impact of sickness on self-concept or identity has also been addressed via patient drawings. Cross, Kabel, & Lysack (2006) explored this with a sample of 160 people paralysed due to spinal cord injury (SCI), 'self' drawings revealing patients' anxieties over how their disability was perceived by others, for example the omission of a wheelchair in some of the drawings reflecting a desire not to be defined by the SCI – that the bodily injury was not indicative of a damaged self. In this study metaphorical images also featured as a category of representations of SCI. Other adult disease populations with whom drawings have been used as a source of information about their experiences include survivors of the ebola virus (Locsin et al, 2003), lupus patients (Nowicka-Sauer, 2007), and psychiatric patients (Pereira, Furegato, & Pereira Jr., 2005).

So both child and adult patients' experiences of illness can be expressed through artistic mediums. The subsequent section will present evidence from a growing body of research which suggests illness beliefs may be embodied in visual form, in patients' mental images of their disease. However it is necessary at this point to first clarify what is meant by a 'mental image', and this will now be defined.

3.7 WHAT IS A 'MENTAL IMAGE'?

In this thesis the term 'mental image' refers to any image of the cancer which is perceived by the patient as existing in the mind's eye – that is an image which is visualised internally in the mind. This definition is drawn from the field of cognitive psychology/neuroscience[4], and so a brief foray into this literature as it pertains to the existence and importance of mental images is appropriate. The capacity of human beings to visualise internally that which they cannot actually see is widely accepted, however the nature and format of mental images and the mechanisms of the brain involved in their generation are still a matter of dispute. Extensive discussion of these issues is beyond the scope of this thesis (which does not seek to answer these questions), so the following discussion will be confined to how this literature has explored the existence and nature of mental images.

Research into internal mental images is particularly challenging because, unlike other cognitive faculties such as language, there is no way to objectively assess this aspect of functioning – there is no way to objectively ascertain what an individual may see in their mind's eye (Bertolo, 2005). Over the past two decades much of the research into mental images has involved monitoring brain activity during visualisation exercises using FMRI (functional magnetic resonance imaging) or PET (positron emission tomography) imaging techniques. The underpinning assumption in this kind of inquiry is that similarity in the areas and mechanisms in the brain involved in actually seeing (referred to as 'visual perception' in this context) and internal visualising suggests a depictive (pictorial) rather

[4] This definition concurs in the basic sense that it refers to 'seeing in the mind's eye' rather than directly observing (Bertolo, 2005). There is in fact some disagreement over the definition of mental (or visual) imagery within these fields, and more sophisticated/complex terminology is often used. For example the term 'mental image' in this literature may also refer to non-visual mental representations (auditory or tactile representations for example), but in this thesis the term will be limited to visual mental representations only.

than descriptive (language-like) format of thought is employed. Investigation of the activation of the brain during such tasks has produced inconsistent results however. For example Kosslyn, Thompson & Alpert (1997) implicated some areas of the primary visual cortex as being involved in visualisation as well as sight, while D'Esposito et al (1997) and Knauff et al (2000) instead demonstrated activation of the 'visual association cortex'.

The inconsistency in the brain activity recorded during visualisation as opposed to visual perception by different studies may be considered to undermine the view that some thoughts require the brain to process them in a visual rather than verbal way, as per actual seeing. Though it has been suggested this is rather a symptom of the complexity of the phenomenon of mental visual images - that there may be different types of image, and different ways of generating images, for which the mechanisms activated in the brain may therefore vary accordingly (Kosslyn, 2005). The notion of different types of mental image has been supported in the literature, in particular a distinction between spatial and visual (or iconic) images has been proposed. Kozhevnikov, Hegarty & Mayer (2002, p48) define these image types as follows:

- Spatial image – A mental representation of the spatial relations between the parts of an object, the location of objects in space, and their movement.
- Visual/iconic image – A mental representation of the visual appearance of an object, such as its shape, size, colour, or brightness.

Empirical support for the existence of these different types of mental images has been provided through numerous studies comparing eye-movement tracking during the evocation of both spatial and visual images. For example a recent small sample study (Sima et al, 2010) noted that eye movements did not appear to mirror spatial properties when participants were asked to solve mental problems based on abstract

information (inducing a spatial image); but did mirror spatial properties when visualising pictorial-type mental images. Such differences support the notion of more than one mechanism of image generation. Sima et al (2010, p251) propose that individuals may employ both spatial and visual images dependent on the requirements or demands of the task, generating the latter where:

> "the stimuli are easy to visualise and contain a lot of vivid and visual details".

The debate around the format of cognitive representations continues, with empirical endeavours continuing to interpret observable data such as brain activation and eye movements in relation to internal visualisation tasks. Such interpretations are fiercely contested however. The very equation of the activation of some areas of the brain involved in vision with 'evidence' of mental images is not universally accepted. One of the most vehement critics is Pylyshyn (2003) who argues that such research reveals nothing about the format of the cognitive representations and that these could equally be non-pictorial with respect to both mental images and actual vision. In other words the form of thought involved in both sight and internal visualising has not been established as pictorial in nature, and so although similar brain processes may be involved this does not confirm the existence of 'pictures in the mind'.

The acknowledged impact of task instructions on the data gleaned from research participants is a central component of Pylyshyn's (2002) rebuttal. He argues that people, when asked to visualise an object, use what he termed their 'tacit knowledge' in order to imagine what it would be like to actually see it, and thus observable effects in terms of brain activity and eye movements is simply a simulation of the effects of actually seeing the object. Why is it then that some people report seeing mental images as if akin to a picture in the brain? Because it makes an intuitive kind of sense he claims, to believe that when a scene is perceived visually (actually seen) or visualised internally (as in a mental

image), that this is depicted in the mind. As Quinlan & Dyson (2008, p243) agree, there is a "seductive" simplicity to the idea that our visual knowledge of the world is stored in the mind just as we perceive and experience it – in a visual, pictorial manner.

One line of research that conflicts with Pylyshyn's (2002) view is that involving studies of internal visualisation with people who have been blind since birth, and therefore have no experience of sight. For example Bertolo (2005) used EEG (electroencephalogram) techniques to assess the visual content of the dreams of both congenitally blind and visually-unimpaired participants, and found the former were able to both visualise and re-create pictorially images from their dreams. This suggests that in fact mental images exist without the need for a 'visual blueprint' in the form of Pylyshyn's (2002) tacit knowledge which enables the simulation of actually perceiving an object when visualising it, as these participants cannot actually see. In other words, internal visualisation – the generation of mental images – is possible without visual experience.

The question of whether mental images do constitute a distinct type of thought, cognitions which are depictive rather than descriptive in form, is potentially unresolvable; and is not the topic of this thesis. As the adopted definition of 'mental image' indicates, the focus of interest is on mental images which are perceived as existing in the mind. The contention here is that people are capable of visualising things internally (creating mental images), and that this can be experienced as if there are mental images in the mind, regardless of whether the actual format of thought is pictorial or non-pictorial in nature.

3.8 WHY INVESTIGATE PATIENTS' MENTAL IMAGES? – POTENTIAL IMPORTANCE AND USEFULNESS

The first part of this chapter showcased some of the research carried out since the publication of the self-regulation model (Leventhal, Meyer & Nerenz, 1980) which has demonstrated the importance of illness beliefs in affecting patients' experiences of illness and health outcomes. In a climate where written assessments of belief dominate however, the importance of investigating patients' mental images of illness will now be explained. This is a two-faceted argument, firstly that knowledge can be visual in nature and may not be communicable using words, and secondly that images can be powerful in their own right, and beliefs embodied in images may potentially be more influential over outcomes than word-based beliefs.

Advocates of visual methods contend that they enable researchers to gain a deeper insight into individuals' experiences by broadening the dimensions of subjective 'knowledge' that can be explored (Guillemin, 2004b; Kearney & Hyle, 2004) – that is visual knowledge in addition to word-based knowledge. If there are indeed different ways of knowing, of understanding the world, then confining research to non-visual cognitions risks overlooking a whole other dimension to patients' experiences.

Images convey meaning in a different way to words – showing rather than telling us information. While communication about images demands verbal description, words cannot fully relate visual information because of this fundamental difference (Lewis, 2001). If patients' beliefs are embedded in mental images, expression of these is likely to be problematic. Indeed both Leventhal and Kleinman recognised that elements of explanatory models of illness may be implicit rather than explicit, and so difficult to verbalise (Leventhal, Meyer, & Nerenz, 1980; Kleinman, 1980). Internal mental images

of disease constitute one form of implicit knowledge, and therefore are perhaps most effectively elicited pictorially.

As well as providing access to a visual dimension of thought, drawings have been commended as a useful tool for stimulating/facilitating discussion with adults (Nowicka-Sauer, 2007) and children. For example in a study of children with asthma, Gabriels et al (2000) found image-production conducive to the expression of emotions about illness, reporting 94% illustrated feelings related to having asthma in their drawings, while only 39% verbalised these. This suggests certain cognitions/ emotions about the meaning of illness may be conveyed more easily or effectively via visual means.

As pictures convey meaning differently, patients' mental images of their disease may communicate different kinds of information to them about the illness, the meaning of which may only be accessible through re-creation of these images. By enabling patients to reproduce these in a research context we may therefore be able to gain a deeper understanding of patients' perceptions of their illness.

3.8.1 THE POWER OF THE VISUAL

If we accept that knowledge may be visual as well as verbal, the relative power of these two forms of knowledge should also be considered. Sociological writers emphasise the visually-dominated nature of postmodern Western culture and the power of imagery in marketing and propaganda (Chaplin, 1994; Rose, 2007). For example, writing from a feminist perspective, Zechmeister (2001) points out the utility of foetal images in anti-abortion campaigns, and the potential threat to women's reproductive freedom. The technology which enables the foetus to be visualised in utero now endows it with a sense of personhood beyond that of the unseen foetus, and thus images may be considered more potent politically. On an individual level, Draper (2001) describes how ultrasound

images affirm the reality of the baby for expectant fathers in a way that other kinds of 'knowledge' about the pregnancy do not. Men, she argues, 'privilege' this visual knowledge in the absence of the somatic indicators of the foetus available to women. The reinforcing effect of scan images has also been reported in women themselves, changing the way women feel about the baby and facilitating bonding with the impending child (Dykes & Stjernqvist, 2001).

The fabled power of images, the privileging of visual knowledge cited by Draper, its potency and the greater trust placed in visual information, goes beyond an individual level and has in fact been identified as a feature of the broader modern Western culture awash with images (Jenks, 1995). Partly the power of images may be explained by the immediacy of their impact (Lewis, 2001), their ability to convey a depth of meaning concisely and evoke a powerful emotional response – arguably more powerful than that which could be elicited by words-based information with its inherently more abstract quality (Stephens, 1998, p62-63).

Though patients' mental images of their disease remain relatively unexplored to date, the power of images has been recognised in health research, and this is evident in the increasing employment of visual strategies in health interventions – for example the recent introduction of pictorial warning labels on cigarette packets in the UK was based on Canadian research indicating that images may promote cessation more effectively than written warnings (Department of Health, 2006). To continue along the theme of smoking cessation, a number of studies have suggested a more significant impact from interventions involving a visual image component. Trials using personalised images of the smoker's own atherosclerotic plaques have moderate success in increasing perceived vulnerability to smoking-related diseases (Shabab, Hall, & Marteau, 2007), and higher quit rates amongst those receiving the photographs compared to standard care (Bovet et

al, 2002). Results such as these suggest that images can potentially communicate information more powerfully or effectively than written text, so if patients do generate mental images of their disease the messages conveyed by these images (how the patient interprets and assigns meaning to it) may be equally – if not more – influential than the messages conveyed by non-visual information in affecting their cognitive and emotional representations of their illness.

3.9 INVESTIGATING THE VISUAL EMBODIMENT OF ILLNESS BELIEFS

To date the body of research which has specifically sought to access illness beliefs by eliciting patients' mental images is relatively small, yet these studies have demonstrated that this is a viable means of investigating patients' perceptions of their illness. For example Anderson & Spencer (2002) found perceptions of the consequences (physical, emotional, and social) and controllability of AIDS heavily embedded in patients' (largely metaphorical) mental images of the disease. Other studies employing visual methods have endeavoured to link specific beliefs embedded in images to the three aspects of illness these may affect – psychological well-being, behaviour, and overall outcomes – and appear to support the hypothesis that patients' mental images too may powerfully influence their experiences. An overview of this literature follows.

3.9.1 IMAGES AND PSYCHOLOGICAL DISTRESS

Using qualitative interviews alongside patients' drawings, Harrow et al (2008) found breast cancer patients' mental images of their cancer embodied positive and negative beliefs, reflecting its physical identity, consequences in terms of behaviour within the body and likelihood of spread or recurrence; and these properties were linked to anxiety over prognosis and fear of recurrence. The distressing potential of disease images was unintentionally revealed in another study, an educational intervention trial

which involved showing adolescent cancer patients samples of their tumour tissue. Post-intervention, a dramatic change was observed in patients' mental images of and attitudes towards their cancer, as patients' original mental images appeared to be replaced with the comparatively less threatening tissue sample pictures, which had a positive effect on their emotional response to the disease (Morgan, Roberts, & Stahlschmidt, 2008). Beliefs embedded in mental images, such as viewing the heart as damaged in the context of heart failure, have also been strongly associated with depression and poorer perceptions of the consequences, timeline, and control potential of the illness (Reynolds et al, 2007).

3.9.2 IMAGES AND BEHAVIOUR

Patients' illness-related behaviours may also be influenced by understandings of their disease based on mental images. A qualitative study of children with cystic fibrosis and their parents (Williams et al, 2007), found those who visualised the physical impact of the condition – the continuous accumulation of mucous in the lungs – perceived the threat to life as more immediate (by virtue of its current processes within the body rather than an eventual far-off consequence of the disease) and were better motivated to adhere to chest physiotherapy. Furthermore, the properties of patients' depictions of illness, as a reflection of their beliefs, may correlate with specific behaviours. For example Broadbent et al (2009) found increased drawing size was associated with a greater restriction in daily activity during headaches, alongside perceptions of more severe symptoms and consequences.

3.9.3 IMAGES AND OUTCOMES

Perhaps the most interesting research into illness beliefs and mental images thus far has been the work of a New Zealand-based research group with heart attack (MI) patients, which demonstrated that patients' perceptions reflected in their images can be linked to

disease outcomes. In their original study of MI patients' drawings of their heart (Broadbent et al, 2004), there were statistically significant differences between the timeline and cure/control perceptions of those who drew damage to their heart, and those who did not. Analysis of the percentage of damage drawn showed it was significantly associated with poorer perceptions of recovery and outcome in terms of time taken to return to work, which was not predicted by any clinical variables – i.e. those who drew/perceived less damage to their heart recovered more quickly regardless of the actual damage. Subsequent research by this group has affirmed the predictive value of patients' drawings with respect to cardiac anxiety (and behaviours indicative of this such as activity restriction and more frequent healthcare-seeking), and a slower return to work (Broadbent et al 2006).

3.10 EXTERNALISING AND ANALYSING PATIENTS' IMAGES OF THEIR DISEASE

There is a deal of uniformity in the methods which have been employed to externalise how patients' visualise their disease. The inadequacy of language to fully represent patients' beliefs was argued in a previous section of this chapter, and this is especially pertinent when trying to access mental images of disease in a research context. This thesis is underpinned by a constructivist perspective which emphasises the subjectivity of meaning and how people view the world. Without the ability to literally see into another's mind and view how the disease is represented pictorially, the closest one can come to understanding patients' internal mental images is by way of external re-creation. Though some studies have relied on the verbal relaying of internal mental images (for example Anderson & Spencer, 2002), participant re-creation via drawing or other artistic mediums has been the preferred choice in research into illness beliefs and mental images, as words, even depicting images, are open to such wide interpretation

that the ability of the researcher to mentally reconstruct a described image with any degree of accuracy is highly questionable.

Patient-produced drawings, then, are the favoured manner of externalising patients' mental images, and there is a remarkable degree of consistency in the methods which have been used to this end. Qualitative studies in this field have solicited directed drawings within an interview context which are then subject to discussion. This is akin to the 'draw-and-write' technique, popularly used with children in numerous settings such as health education research and clinical practice (Backett-Milburn & McKie, 1999). Typically, the participant is provided with a blank piece of paper and drawing materials and invited to draw how they visualise their condition (for example Guillemin, 2004a; Nowicka-Sauer, 2007; Harrow et al, 2008). Quantitative approaches, such as the seminal work of Broadbent and colleagues (2004; 2006), have included image re-creation as part of a battery of self-administered questionnaires with standard written instructions.

An important distinction between the use of drawings as an additional qualitative data source and in the quantitative work of Broadbent cited earlier, for example, is the utilisation of participants' own explanations of the drawings in determining meaning in the former; and objective, rater-assessed analysis in the latter. Like words, the interpretation of images is also highly subjective (Stephens, 1998), and in recognition of this an essential consensus exists amongst qualitative researchers that patients' drawings must be analysed in conjunction with participants' explanations of their meaning (Guillemin, 2004b; Cross, Kabel, & Lysack, 2006). As Nodelman (1988, p211) puts it:

> "Pictures can communicate much to us, and particularly much of visual significance – but only if words focus them, tell us what it is about them that might be worth paying attention to."

The alternate, quantitative approach to analysis has thus far been two-pronged – marrying examination of the content of drawings with theoretically-informed examination of their scale. Content analysis can be as simplistic as distinguishing between the presence or absence of damage drawn in cardiac patients' post-MI drawings of their hearts, suggesting perceptions of its physical consequences (Broadbent et al, 2004; Broadbent et al, 2006); or the presence of an external force to the head in patients' headache drawings correlated with worse pain (Broadbent et al, 2009). The more recent work published by the Broadbent group has used the 'size-importance hypothesis' to inform analysis (Broadbent et al, 2006; Reynolds et al, 2007; Broadbent et al, 2009). This theory contends that the importance or primacy of a drawn topic to the drawer is reflected in increased size. Although Thomas & Jolley (1998) have been critical of inferring emotional significance from features of drawings such as size, their concerns over the credibility of such methods are levelled at studies where pictures are the sole measure. In the three recent studies cited above (Broadbent et al, 2006; Reynolds et al, 2007; Broadbent et al, 2009) drawings have been analysed in conjunction with other quantitative measures such as the 'Brief Illness Perceptions Questionnaire' (Brief IPQ), and the authors have demonstrated a consistent link between larger drawing size and greater anxiety, suggesting size can be used as an indicator of illness-focus.

3.11 CRITICISMS OF VISUAL METHODS

Many of the criticisms of visual methods have been voiced in reference to the use of drawings to assess the beliefs and feelings of children, pointing to the potential complexity and ambiguity of these (Thomas & Jolley, 1998), and questioning the

assumption that drawings are a direct reflection of internal thoughts and feelings (Backett-Milburn & McKie, 1999). In response to these concerns, advocates of the use of drawings in research with adults recommend that it is always combined with other modes of data collection, and that participants' explanations of their drawings are elicited also to form a solid basis for analysis (Guillemin, 2004b; Cross, Kabel, & Lysack, 2006). Within a qualitative perspective the subjective nature of interpreting any kind of data is acknowledged, and while images may be considered even more open to inconsistent perceptions of meaning (Stephens, 1998, p66), if accompanied by a verbal account there is no reason to presume the analysis will be any less credible than that of written data. We would therefore concur with Guillemin (2004b), who points out that such criticisms stem from a positivist worldview which sees the goal of research as establishing an objective truth, incongruent with a qualitative approach, and in fact drawings may be a useful additional research tool for exploring patients' experiences and understandings of their illness.

3.12 THE EXPLORATORY AIMS OF THE THESIS

This chapter has presented a portion of the wealth of existing research into patients' perceptions of their illness and how these affect outcomes. However the current verbal and textual bias in how research approaches illness beliefs means an important dimension of patients' experiences and understandings of their illness is being overlooked. The fabled potency of imagery in a visually-dominated culture is reflected in the increasing interest in imagery-based health interventions, and some promising findings in this area support the potential power of mental images in patients' cognitive representations of their disease.

3.12.1 THE RELATIVELY UNCHARTED WATERS OF ADULT IMAGES OF ILLNESS

To date visual methods have traditionally been utilised with child patients and to a lesser extent with adults, as a means of communicating their experiences of being sick. A small but growing body of research has indicated that patients' drawings may also be a viable method of accessing their illness perceptions, and that patients' mental images of illness may also factor powerfully in psychological, behavioural, and health outcomes. Research into adult images of illness is in its infancy however, and this aspect of patients' experiences has thus far been largely neglected. Presently several fundamental questions pertinent to researching the phenomenon of mental images remained unanswered. These concern how best to access patients' images, their nature, form, and significance, and how they relate to illness beliefs. This thesis will therefore address these basic questions, and will aim to:

1. Establish a feasible method of accessing and externalising patients' internal mental images of the cancer.
2. Characterise the manner and extent to which head and neck cancer patients may visualise their disease, and the common parameters of such images.
3. Investigate the role of different forms of imagery, both anatomical and metaphorical, in patients' understandings and experiences of their cancer.
4. Clarify the perceived origins of these images.
5. Explore the relationship between patients' images of the cancer and their illness beliefs.

3.12.2 HNC PATIENTS AS AN IDEAL STUDY POPULATION

Head and neck cancer patients typically compose of a deprived group who experience significant functional and psychological difficulties as a result of their disease. They are also likely to engage in behaviours detrimental to good prognosis such as continued smoking or drinking, and therefore are a patient group arguably in great need of

interventions to improve outcomes. Despite this, qualitative research with head and neck patients is comparatively lacking, and relatively little is known about their experiences and understandings of their cancer – as this may relate to mental images or otherwise. Cancer is a particularly fruitful disease for research into patients' mental images, as it is an illness which is often physically hidden, whose progression is regularly assessed in visual form through scans and x-rays, and which is culturally enshrined in metaphors and euphemisms. Patients with head and neck cancer may be able to feel or even see their cancer, and it is unclear whether the potentially visible disfigurement associated with their cancer or its treatment adds any additional significance to how they may visualise it. This thesis will use qualitative methods to explore head and neck cancer patients' mental images of their disease, and the importance of these in the context of their illness beliefs and overall experiences. The following chapter will present the methodological approach to this endeavour in detail.

4 DEVELOPING THE METHODOLOGICAL APPROACH

The purpose of this project was to gain an insight into the experience of head and neck cancer, and particularly to explore the hitherto neglected phenomenon mental images of the cancer and the relationship of such images to patients' beliefs and understanding of their experience. Such a focus demanded a qualitative methodological approach, and this mandate was addressed by way of three empirical ventures:

1. An exploratory pilot study (Chapter 5)
2. A metasynthesis of existing qualitative research (Chapters 6 and 7)
3. A larger longitudinal study (Chapters 8 and 9)

These endeavours were underpinned by a constructivist philosophy which contends that 'reality' is a relative phenomenon, and as such the goal of research is not to discover an objective truth, but to credibly interpret and represent others' subjective reality. To meet the study objectives with respect to the pilot and longitudinal studies a qualitative approach was adopted, with semi-structured interviewing selected as the method of data collection, an approach which required consideration of a number of ethical issues.

The first part of this chapter will outline the philosophical stance and theoretical background to the project. It will go on to justify the methodological perspective for the design of the pilot and main studies, and then describe some of the ethical issues intrinsic to undertaking this kind of research with head and neck cancer patients. The metasynthesis methodology is not referred to here as it is a wholly literary exercise, and these considerations do not apply. Precise details of how the methodological approach was operationalised with respect to all three components of the project are located within each of the respective chapters.

4.1 THE CONTEXT OF THE METHODOLOGICAL DESIGN

The methodological design of this project was determined by a network of underlying philosophical and theoretical assumptions. It is necessary to explicate these assumptions as they constitute the context in which this research must be understood and appraised, as different methodological standards apply depending on what kind of knowledge one is seeking, and how one believes it may be revealed (Morrow, 2007). This section will therefore explain the philosophical background to the project, and briefly revisit the core theory which informed the development of the two research studies.

4.1.1 PHILOSOPHICAL ORIENTATION: CONSTRUCTIVIST PARADIGM

The philosophical orientation or paradigm refers to those assumptions concerning what can be 'known' upon which any research endeavour is founded. It is comprised of beliefs about what reality is (ontology), and in what way we can learn about it (epistemology); these beliefs drive the design of research. Guba and Lincoln (1994, p105) conceptualise a paradigm as:

> "The basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways."

It is necessary then to make the underlying worldview upon which the empirical components of this thesis were founded explicit, and that is the constructivist paradigm. Constructivism diverges from the positivist tradition – which governs the natural sciences and much quantitative research – in two essential ways.

The ontological view concerns the nature of reality, and whether or not there is an objective reality which can be measured or observed and about which we can discover essential 'truths' – as per positivist thinking. Such a reality is an apt foundation for much

quantitative research – and is not necessarily inconsistent with some qualitative approaches (Guba & Lincoln, 1994) – it is certainly suitable for investigations in biological science or physics for example.

In contrast, a constructivist ontology proposes that there is not one universal or 'real' reality, it is a relative concept, and multiple versions of it exist, constructed in the minds of individuals, influenced by social and experiential factors, and to differing extents shared among communities/cultures. Because reality is constructed, the criteria of truth and falseness are irrelevant, instead there are varying degrees of construct sophistication (Guba & Lincoln, 1994). That which is considered to be true objective knowledge is in fact an interpretation based on a subjective, relative standpoint (Schwandt, 1994).

The epistemological perspective refers to the relationship between the researcher and what can be learned. In opposition to the positivist view, the researcher is not observing the object of study in a vacuum and bearing no influence upon it, they are an integral part of the equation, and their interaction with the topic of study means there is a subjective element to the 'knowledge' that can be extracted – the findings produced are created or constructed by means of this interaction (Guba & Lincoln, 1994).

The belief in multiple, relative, constructed realities, and in the transactional and subjective nature of relations between the researcher and the object of study, have certain implications for the design and conduct of research. In accordance with this perspective, the methodology advocated within the constructivist paradigm emphasises the researcher's role as a participant in the investigation who impacts on the data collection and analysis. In his delineation of constructivist and interpretivist paradigms,

Schwandt (1994, p119) outlines various competing ideas regarding the tension between subjectivity and objectivity, and illustrates one viewpoint thus:

> "…Fully accepting the hermeneutical character of experience… The activity of interpretation is not simply a methodological option open to the social scientist, but rather the very condition of human inquiry itself."

The empirical methods adopted in this thesis are congruent with this philosophical stance, and consistent with Heidegger's concept of fore-structures which proposes that all 'knowledge' is interpretive in nature, and that existing knowledge is revealed through the research interpretation (Mackey, 2005), and this is expanded upon in the following section.

4.1.2 ELEMENTS OF PHENOMENOLOGY

Phenomenology originated as a philosophical movement, and while elements may be traced back further, Edmund Husserl's work at the turn of the twentieth century is credited with establishing it as a philosophical discipline (Moran, 2000). There are three essential features of Husserl's phenomenology: the goal of exposing subjective understandings of experiences, and striving to elicit their underlying structures via reasoned interpretation; the adoption of an inductive approach in the study of singular aspects of the phenomenon, moving towards a logical discernment of the 'universal principles' of the broader object of study; and the positivist character of this stance:

> "Searching for the universal and irrefutable… the truth lying at the heart of every feature of human experience" (Hallett, 1995, p57)

In order to engage in objective inductive reasoning, Husserl proposed it necessary to first 'bracket' or set aside one's prior beliefs, knowledge, and experiences of the phenomenon under scrutiny (Bryne, 2001). The prevailing perspective or attitude must be suspended to enable one to achieve genuine insight into the object of study (Moran, 2000).

Martin Heidegger started life as a student of Husserl's, and went on to elaborate upon and overhaul certain features of the approach and develop a viewpoint of his own (Moran, 2000). Heidegger's phenomenology differs crucially in its contention that the world and phenomena cannot be understood purely objectively, out-with the context of the individual's experience of 'being-in-the-world' and the temporal and spatial properties of this (time and space). He coined the term 'fore-structures' to refer to the previous knowledge, experiences, and interpretations which are brought to the research, and this is the fourth key concept of Heidegger's (Mackey, 2005). Essentially this stance is very relativist in nature.

Things must be interpreted in order to have meaning, and interpretation in research facilitates the expression of existing interpretations – this is a circular endeavour comprising the explication of existing fore-structures, and iterative reflection on the pieces of the puzzle and the whole picture. The concept of the 'hermeneutic circle' – hermeneutics being the interpretation of texts – represents this process by which an understanding is developed by repeatedly considering aspects of the phenomenon individually, and as a whole (Mackey, 2005).

The work of these two key protagonists inspired numerous other theorists such as Jean-Paul Sartre, Maurice Merleau-Ponty, and Hans-Georg Gadamer, to weigh in, and a vast spectrum of philosophical and methodological ideas have been developed derived from

these phenomenological roots (Moran, 2000). Phenomenology is fundamentally an umbrella term which encompasses myriad perspectives and approaches to studying various phenomena, and is far from a unified field. As Moran (2000, p3) comments:

> "It is important not to exaggerate… the extent to which phenomenology coheres into an agreed method, or accepts one theoretical outlook, or one set of philosophical theses about consciousness, knowledge, and the world… The philosophers who in some sense identified with the practice of phenomenology are extraordinarily diverse in their interests, in their interpretation of the central issues of phenomenology, [and] in their application of what they understood to be the phenomenological method."

So within the aforementioned constructivist paradigm, the principles of the relative nature of interpretation, the focus on context, and the acknowledgement of the researcher's role in the research process, drawn from the Heidegger branch of this complex and confusing field of phenomenology, guided the conception and conduct of this research.

As Hallett (1995) noted, Husserlian phenomenology is based on the search for the universal 'essences' of human experience of phenomena – or 'absolute truths', and while it involves a process of interpretation, this positivist ontology is difficult to reconcile with a constructivist paradigm which emphasises the relative nature of interpretations. Therefore our approach is more congruent with the broad principles of Heideggerian phenomenology – one must engage in descriptive and interpretive activities; the focus is on the person and the context of their existence; and the interpretation is of a subjective and relative nature (Mackey, 2005). The attempt to elucidate and acknowledge the role of the researcher's own prior conceptions (Heidegger's 'fore-structures') is one aspect of 'reflexivity', which is outlined further later in this chapter.

4.1.3 DRAWING ON THE CONCEPT OF 'ILLNESS REPRESENTATIONS'

A crucial divergence from the perspective of Heideggerian phenomenology in the design of our studies is that while we are seeking to understand the subjective meaning of head and neck cancer patients' experiences, and particularly the role of mental images in these, the analysis is not structured explicitly along the lines of being-in-the-world and lived space and time, as per Heidegger's focus – though elements of these concepts are arguably inherent within any study of human experience. Instead at the heart of our investigation lie the five dimensions of Leventhal's 'illness representations' drawn from the self-regulation model (which was outlined in depth in Chapter 3) – a concept which provides a useful framework for exploring patients' illness beliefs.

Leventhal proposed that the cognitive component of patients' illness representations comprised beliefs concerning five essential aspects of the illness - identity, cause, consequences, timeline, and cure/control (Leventhal, Meyer & Nerenz, 1980). The existence of beliefs which fall into these five broad categories among patient populations has been amply borne out by the literature, as demonstrated in the preceding chapter. The focus of this project was not to establish the validity of Leventhal's model, nor to explicitly apply the illness representation concept to patients' mental images and understandings of their cancer. Rather the broader self-regulation model formed the scientific basis for this project and informed its development, while the concept of illness representations provided a preliminary tool for classifying and interpreting patients' beliefs and the interviews and the subsequent analysis of the data was initially organised according to, but not constrained by, this concept.

The utilisation of existing theory in this way is not incongruent with the overarching approach to the thesis however. As intimated in the preceding section, Heidegger's phenomenology rejects the idea that one can 'bracket' one's existing knowledge,

assumptions and biases, and instead advocates critical explication of these. So while this theory informed the execution of the research, it was not defining. In qualitative terms, cognisance of existing relevant theory may enhance theoretical sensitivity in the researcher's interpretation of their own empirical data. The application of a theoretical understanding then enables the data to be considered in context of the wider literature, as well as purely inductively (Andersen & Kragh, 2010).

4.1.4 A SYNOPSIS OF THE METHODOLOGICAL STANCE

The broad guiding philosophical and theoretical underpinnings of this qualitative thesis then can be summarised as falling within a constructivist paradigm, embracing the principles of context, relativity, interpretation, and the focus on the person drawn from Heideggerian phenomenology, and informed by the concept of illness representations drawn from Leventhal's self-regulation model. It is an exploratory and inductive project, informed by theory.

4.2 METHODOLOGICAL PERSPECTIVE OF THE TWO STUDIES

This project incorporated two research studies alongside a literature-based piece of original work in the form of a metasynthesis. The latter's methods are reported in full in the pertinent chapter (6). However the two research studies – an exploratory pilot followed by a larger longitudinal study – derive from a common methodological perspective and both employed semi-structured qualitative interviewing as the method of data collection. Therefore both studies were subject to shared methodological, practical and ethical considerations, and so to avoid repetition in the studies' respective chapters later, this common background will now be outlined.

4.3 A QUALITATIVE MODE OF INQUIRY

The remit of this thesis was to investigate and explore the existence, meaning, and importance of head and neck cancer patients' mental images of their disease, and how they relate to their illness beliefs. The appropriate mode of inquiry to address these issues was dictated by the type of information sought, with the following tentative research questions having been developed from the literature:

1. In what ways and to what extent do patients with head and neck cancer visualise their cancer?
2. What form do patients' mental images of the cancer take (i.e. anatomical, metaphorical, abstract)?
3. What are the origins of these images?
4. What is the relationship between patients' mental images of their cancer and their illness beliefs?

Quantitative methods are used to elicit data which can be analysed statistically or numerically, to answer questions about incidences of certain behaviours or attitudes within a given population (Pope & Mays, 1995) - for example 'how many pregnant women continue to smoke during pregnancy?' Such data can then be interrogated to reveal factors which are associated with maternal smoking, and to refute or support hypotheses.

The present concern was not to measure the prevalence of mental images of cancer among HNC patients however, but to investigate their meaning for patients – a question best addressed using qualitative methods which seek to elucidate the meanings people attach to their experiences and how they understand the world (Pope & Mays, 1995; Morrow, 2007). Qualitative methods yield detailed and descriptive data (Gray, 2009), and enable a more intensive investigation of specific issues by employing smaller sample

sizes and being less constrictive in terms of study focus (Patton, 1990). The exploratory and novel nature of this project therefore dictated the use of qualitative methods.

Qualitative methodology is inductive, and eschews the imposition of pre-existing theories or concepts onto the data, as the aim is to develop an understanding of the topic which is grounded in the data itself. The previous section explained the key role of Leventhal's concept of illness representations in the development of this project, something which may appear at odds with an inductive approach. It would be misleading to assume that most research is wholly inductive however, as the scope and focus of the study, and research questions of interest, are often defined beforehand – with the caveat that the researcher is not constrained by these, and is open to pursuing unanticipated questions and findings which may arise. The setting of these kinds of boundaries enables some structure to be applied to the process, and avoids the accumulation of the vast amounts of data which would be yielded if the design was entirely inductive and unstructured (Gray, 2009, p175), an impractical approach given the theoretical background to, and practical and applied nature of, this PhD studentship.

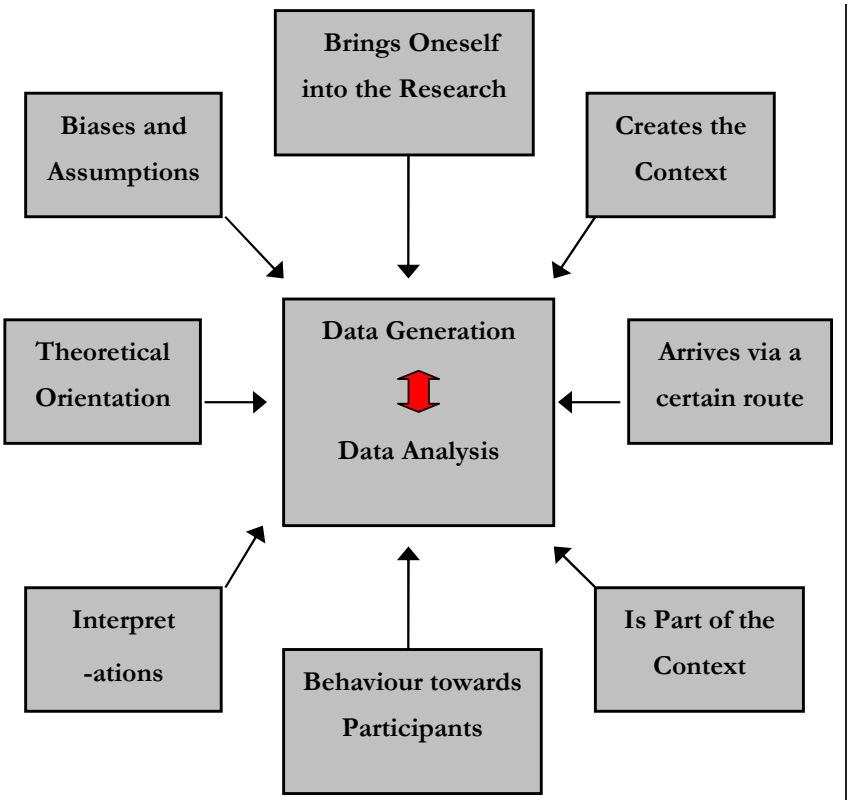
The informative use, rather than strict application, of Leventhal's theory in this project is therefore not inconsistent with the inductive nature of qualitative research, when utilised in the appropriate manner, as clarified by Morse (1994, p221):

> "In qualitative inquiry the theory is used to focus the inquiry and give it boundaries for comparison in facilitating the development of the theoretical or conceptual outcomes… At best [it] may be considered a conceptual template with which to compare and contrast results, rather than to use as a priori categories into which to force the analysis."

The human and subjective elements of research are emphasised within the qualitative perspective and this is congruent with the philosophical underpinnings of this project which reject the notion of an objective reality which can be measured. While quantitative ideology is largely dismissive of the influence of personal and contextual factors in research, claiming to negate this through the standardisation of study methods (Diefenbach, 2009), qualitative work is judged by a different set of standards, and acknowledges the role of such factors. Historically cited as a devaluing facet of this type of research, the contribution qualitative methods can make to our understanding of people and their experiences, in spite of its self-confessed subjectivity, has now been widely acknowledged (Finlay, 2002), and a critical awareness of the lack of objectivity in the research process and findings of qualitative research – referred to as 'reflexivity' – is advocated.

Reflexivity is a key tenet of qualitative methodology in terms of ensuring the validity or credibility of the findings as derived from the data (Schwandt, 1997, p136). Defined most simply by Mays & Pope (2000, p51) as "… sensitivity to the ways in which the researcher and the research process have shaped the collected data", reflexivity involves critically examining overt and covert factors which may impact upon the conduct of the research, data generation, analysis, and findings. In the broadest sense, the scope of critical reflection should encompass one's own personal and intellectual experiences, biases, and assumptions; and those practical, personal and design factors relevant to the process, context, and relationships with participants and others involved (see figure 3).

Figure 3 – The Scope of Reflexivity: The Researcher's Influence on the Generation and Interpretation of Data



Throughout the project the researcher strived to reflect critically on these issues, a process enhanced by the keeping of a project diary, and detailed field notes during interviews, something which has become relatively common practice to this end. However, reflexivity is largely an internalised process. It is a thoughtful, discursive mindset which is should be applied to the research project; it is an attitude of continual reflection on matters while 'in the moment', rather than retrospectively (Finlay, 2002). The reflexive mindset cannot be achieved by following a set of prescribed behaviours, though practical ways of 'doing reflexivity' have been mooted in the literature to aid researchers to reflect on issues relating to their role in the research (Robson, 2002, p173; Bolam, Gleeson & Murphy, 2003). While difficult to communicate the complex 'output' of a reflexive approach fully – or indeed appropriately, without descending into the kind of self-indulgent navel gazing which results in the real focus of the study being lost (Finlay, 2002) – aspects of this will be delineated throughout this thesis.

The philosophical and theoretical orientation of the project has already been explicated in this chapter. Issues pertinent to the data collection process in the two studies will be outlined subsequently in this chapter, while reflections on specific influences regarding data collection and analysis, and the personal and intellectual biases which revealed themselves as the project progressed will permeate chapters 5 and 7, and consideration of the overall credibility of the project in this respect is outlined in the final discussion chapter.

4.4 DATA COLLECTION

Data may be collected in qualitative research by means of observational or interview methods, or by studying textual or electronic sources (Suzuki et al, 2007). Again, the suitability of particular methods depends on the type of questions one wishes to answer, and the accessibility of the phenomenon of study. Documentary analysis or the use of observational methods are only practicable when relevant data are naturally occurring – that is when pertinent documents are in existence or the topic of interest is observable, such as communication between doctors and patients (Ritchie & Lewis, 2003). In this case, as the focus was on unobservable phenomena - patients' beliefs, experiences, and images of their cancer - our only recourse was to elicit information from the patients themselves, and this required some form of interviewing, a research method founded on the assumption:

> "That the perspective of others is meaningful, knowable, and able to be made explicit." (Patton, 1990, p278)

There are various types of interview formats, and these are outlined in table 5.

Table 5 – Main Types of Interviewing (Fontana & Frey, 1994; Suzuki et al, 2007)

Interview Format	Features
Structured	Standardised set of questions Pre-set response choices Conduct of interviews standardised (phrasing/sequence of questions and interaction with participants) Minimal divergence from procedure
Semi-structured	Specified areas to cover Flexible in sequence of discussion Exploration of new topics raised by participants Open questions, focus on depth/fullness of responses
Unstructured or Ethnographic	Interviews conducted in a very informal manner Topics of interest are raised during interactions with participants in naturalistic settings ('in the field') Key focus is understanding
Focus group	A group of participants encouraged to discuss and share views/experiences Facilitated by the researcher Range in level of structure Enables study of group dynamics

Rigidly structured interviews are more usually the preserve of quantitative studies which demand standardised data collection to avoid introducing biases into the responses. Nor were completely unstructured interviews feasible to achieve the study aims as specific areas of interest and research questions had been identified through the literature review. Therefore two possibilities remained by which to collect data – semi-structured interviews or focus groups. Focus groups excel where the remit of the research is purely exploratory as the discussion may be directed more by the informants themselves where this is suitable. They also offer the opportunity to study divergence and concurrence in perspectives through observing the interactions of the group. However, the depth of information which can be gathered from particular individuals is lessened due to the group format and limitations on the time each person has to speak (Morgan, 1997).

The potential for obtaining more detailed information on an individual level was the primary factor in opting for semi-structured one-to-one interviewing over focus groups as the mode of data collection. Other factors in this decision included the ability to gain insight into the personal circumstances and contexts which underpin patients' interpretations of their experiences, and the greater opportunity for clarification and expansion upon points raised when discussing complex issues (Ritchie & Spencer, 2003).

Further, given that traditionally head and neck cancer patients have been considered a 'hard-to-reach' group due to the disease's association with low socioeconomic status (Parry et al, 2001), it was recognised that interviews would be more accessible and convenient for participants as they could be carried out at their homes, rather than requiring a mass gathering at some location entailing the hassle of travelling and transport, which can be off-putting to patients considering taking part (Ritchie & Spencer, 2003).

Semi-structured interviewing was therefore adopted as the data collection method of choice for both research studies. Specific details of the conduct, settings, and explicit content of the interviews are provided in the relevant sections of Chapters 5 and 7, as are details of how the data were analysed in each case.

4.4.1 SEMI-STRUCTURED INTERVIEWING

Semi-structured one-to-one interviewing is a flexible approach to data collection, particularly suited where the aim is to gain an in-depth insight into another's perspective (Morgan, 1997). Interviews are directed by way of a prepared 'topic guide' which lists the issues to be covered, but the application of this is non-standardised. The depth to which issues are addressed, and the wording and sequencing of questions, is decided by the researcher during the course of the interview. The semi-structured approach

facilitates a conversational style of encounter, with scope for the researcher to probe points raised as extensively as is helpful, and to pursue new or unanticipated issues as they arise during the interviews (Gray, 2009, p373).

In his seminal guide to qualitative interviewing, Kvale (1996, p145) advanced six quality criteria which the researcher undertaking this kind of approach to data collection should strive for. These are:

1. Detailed, rich, spontaneous and relevant responses from the participant.
2. Concise questioning which elicits extensive answers.
3. Appropriate and sufficiently detailed follow-up of pertinent aspects of participants' responses, and clarification of meaning.
4. Interpretation of meaning throughout the interview.
5. Verification of said interpretations of participants' responses during the interview.
6. The transcript of the interview should be 'self-communicating' - a self-contained story which does not require substantial additional description for the content/meaning to be understood.

Essentially the aim is to elicit an account from participants of sufficient depth or 'richness' that it can provide meaningful insight into their perspective or experiences. Questions asked by the researcher should ideally be short and non-directive, allowing participants to respond in their own language. The researcher's role is to listen attentively, probe for more detail as required, and continually interpret and clarify the meanings of participants' responses. These guidelines formed the template for the researcher's conduct and questioning during the interviews.

The qualitative data gleaned by way of the interaction between a researcher and participant during an interview is 'co-constructed'. This means that the way in which the

two parties engage with each other determines the data which is generated, data is constructed and meaning negotiated via their relations, and not solely the product of the participant. Therefore were the interview repeated with a different researcher, in a different context, or under a different set of conditions, the findings would likely differ (Finlay, 2002; Manderson, Bennett, & Andajani-Sutjahjo, 2006; Suzuki et al, 2007).

A successful interview depends largely on the quality of relationship which is established between researcher and participant. Developing a good rapport is essential to enable the participant to engage in an open and honest dialogue, and trust must be built if they are to share intimate details about themselves with the researcher (Gaglio, Nelson & King, 2006; Guillemin & Heggen, 2009). The extent to which a good rapport can be created, and subsequently the quality or richness of the data which is generated, is influenced by the perceived boundaries in the interview situation, level of formality, personal capacities for intimacy, and the personal characteristics and social identities of both parties (Hewitt, 2007), and this is discussed further in the following section.

The strength of interviewing as a means of finding things out 'from the horse's mouth' as it were, is also however its weakness. Like any study based on self-reported data, people may be selective in what they choose to disclose, will be swayed in disclosure by their own biases and assumptions, by social desirability – i.e. saying what they imagine one wants to hear or what is socially acceptable – and by their mood, perceptions of the researcher, and innumerable other factors (Collins, Shattell, & Thomas, 2005; Hewitt, 2007). The recognition of these issues is not intended to undermine the value or worth of this kind of research however, indeed from the constructivist stance adopted in this thesis it would be argued that all 'evidence' gained from interaction with human beings – even quantitative surveys – is subject to these constraints and biases. For example people are known to under-report alcohol consumption in questionnaires, as per social desirability

(Davis, Thake & Vilhena, 2010), a factor which also influences the accounts people give in interviews (Entwistle, Tritter, & Calnan, 2002). Constructivist ontology proposes that interpretation is a facet of the human condition – that all 'knowledge' is constructed by individuals, who interpret the world through their own particular lens, coloured by their social status, and life experiences – and therefore true objectivity is an unattainable goal anyway, and thus not an appropriate basis for assigning scientific merit (Schwandt, 1994).

4.4.2 REFLEXIVE CONSIDERATIONS IN INTERVIEWING

Essentially 'who you are' – as the participant sees you – will affect what information they share with you in an interview situation (Richards & Emslie, 2000); in the same manner as the researcher's own perceptions of the participant will affect how they interact with them, phrase questions, and manage the interview. Reflexivity demands a critical awareness therefore of how participants may perceive us as researchers, and indeed how we perceive them. This section will outline some of the general issues pertinent to the researcher-participant interaction, and explicate some of my own background and identity where this is relevant.

The social standing of the researcher and participant(s) in relation to each other is considered a key factor of influence in the generation of data. Often this is conceptualised simply as whether the researcher is an 'insider' or 'outsider' – that is whether they are a part or 'one of' of the community under study, or do not share the same social position or identity of participants. In this project I was a firmly designated outsider, never having had cancer myself, and this was communicated to participants who were regarded as able to provide meaningful insights into their own experiences of cancer as insiders. Suzuki et al (2007) caution against viewing the researcher's position in purely one-dimensional terms however (simply whether they share the same occupation,

class, gender or sexuality as participants for example), as we all hold multiple identities, and the interplay between different facets of these is more complex than can be reduced to simply insider versus outsider.

Gender is arguably the most marked indicator of difference, and differences in the ways males and females are socialised can influence how they articulate themselves, express emotions, and relate to the opposite sex. In one of the few empirical attempts to compare same- and cross-gender interviewing, Padfield & Proctor (1996) discovered the influence of gender is not simplistic, but depends on how gender roles are negotiated in the interview situation via the researcher's behaviour and participants' own biases. In other words, it does not necessarily follow that a woman would find it preferable to talk to another woman, or vice versa. It should be remembered that both parties are encumbered by their status as 'gendered beings', and that sameness or difference can equally lead to difficulties, for example identification with the participant as a woman – and the shared understanding which may be presupposed – could lead to presumptions of meaning on the part of the researcher, and less rigorous probing (Hamberg & Johansson, 1999).

As a PhD student with no postgraduate experience, I was approaching this project as a novice with very limited experience of qualitative research. This translated into an overall tentativeness, which combined with my relatively young age, short stature, and female gender, meant that rather than holding the power in interview situations – something generally considered to be weighted in the researcher's favour (Eide & Kahn, 2008) – I often struggled to direct the flow of the interview, and was frequently steered off course onto tangents wholly irrelevant to the purpose of the studies, such as participants' hobbies and life in the armed forces. This was not entirely negative, providing a degree of useful contextual information by which to interpret participants'

accounts, but did result in some omissions of pertinent questions and failure to sufficiently follow-up points raised, particularly in the early interviews. While striving to create a conversational atmosphere, there was also substantial use of direct questioning throughout the interviews, a style which has been ascribed to younger researchers (Manderson, Bennett, & Andajani-Sutjahjo, 2006), and may have been a reflection of my lack of experience/confidence in interviewing.

Many clinician-researchers have recounted difficulties due to the competing demands of dual professional roles in the research setting, being both an 'off-duty' midwife (Carolan, 2003) or nurse (Eide & Kahn, 2008) for example, as well as a researcher, with the different goals and professional boundaries this entails. As a non-clinical researcher I was unencumbered by this kind of role-conflict, the only competing demand in the interviews being concern for participants' emotional well-being. Richards & Emslie (2000) noted that being "the girl from the university" as opposed to a GP carrying out research influenced the content of interviews, and seemed to afford more freedom to participants to be critical of health services, a topic pertinent to participants' stories in this project. As simply 'a girl from the university', my own lack of medical knowledge may have been to further advantage, as participants were forced to explain their diagnosis, and the process and nature of their treatments, in great detail to me. Whereas they may not have gone into such depth if speaking to a medically-trained person, as there could be a presumption of mutual understanding in that case (as per Hamberg & Johansson, 1999, cited previously re gender). As participants' understandings of their cancer and treatments were a focus of this project, my position as a lay person may therefore have been advantageous.

4.5 ETHICAL CONSIDERATIONS

The final section of this chapter will describe the ethical issues which had to be considered before undertaking the two research studies in this project. Gray (2009, p69) defines an ethical approach to research as: "conducting research in a responsible and morally defensible way". Primarily concerned with the safety and wellbeing of participants, this section will cover issues of informed consent, confidentiality, and gaining approval from the research ethics committee, which are common to any research undertaking. The latter part will outline issues which are specific to the design of these studies – interviewing cancer patients, potential difficulties unique to those with head and neck cancer, and the safety of the researcher.

4.5.1 INFORMED CONSENT

Gaining informed consent from participants is a legal and ethical requirement for the overwhelming majority of research projects, and is one key focus for ethics committees reviewing proposals. The Royal College of Nursing (2005) cites the following information which must be provided to prospective participants in order for them to make an informed decision and give informed consent:

- The purpose of the research and their role in it if they agree to participate
- The practical nature of participation - explicit details of what it will involve
- The benefits and risks of taking part
- How the data collected will be managed and utilised
- The voluntary nature of participation
- Their right to withdraw from the study at any time, without stating a reason
- The fact that the medical care they receive will not be affected in any way
- Details of the organisation sponsoring the research, the funding body, and the ethics committee which approved it
- Contact details for a relevant party who can provide information

Accordingly, the above information was incorporated into the information sheets for both studies (see appendices 1, 2, 3 for pilot study, and 4 for longitudinal study), and reinforced during discussion with potential participants. The different aspects of the consent form were also discussed prior to signing it.

Verbal consent was established during the initial discussion of the study with prospective participants (in person for the pilot study, and over the telephone for the main study). Prospective participants had the opportunity to take information sheets away with them, and were encouraged to voice any queries at follow-up. The information sheet stated clearly that their participation was voluntary, the decision to take part or not would not affect the medical care they received in any way, and that they could withdraw from the study at any time without having to give a reason. Prior to commencing the interview participants were again given an opportunity to ask questions or raise any concerns they had. Their rights to refuse to answer any question, to terminate the interview, or to withdraw completely were reiterated verbally at this point.

Audio-recording of the interviews – and video-recording of image re-creation in the pilot study – took place only with the participants' consent. It was stipulated at the outset that refusal to be recorded would not compromise involvement in the study, and those who did not consent would still be eligible to participate, with the conversation hand-written by the researcher. In the event, all of the participants consented to audio, and where relevant video, recording.

Consent forms were signed on the day of, but prior to, the interviews - and it was again emphasised that the official giving of written consent in this way did not preclude their right to withdraw from the study at any time. Individuals who lacked the capacity to

provide informed consent – for example due to conditions which impair cognitive abilities such as dementia – were excluded from participating.

While the ethical necessity to gain informed consent from participants is indisputable, it is noteworthy that some of the participants – while not explicitly stating the fact – appeared to decide to take part without having read the information sheet. This exhibited itself at various points throughout our contact when patients expressed uncertainty about their role in the research, the purpose of the study, or indeed the content of the interviews. In such instances the aims and nature of study participation were reiterated, and consent to proceed renegotiated.

4.5.2 CONFIDENTIALITY

There is a legal and ethical imperative to maintain the confidentiality of research participants, and there are several facets to this. Confidential information was – and continues to be – stored securely in locked drawers and password-protected computer files accessible only to the research team. Full transcripts are stored securely in a locked filing cabinet within the University, and will be held for 10 years. Anonymised quotes and the images created by participants will be retained indefinitely however, and explicit consent was sought for this purpose.

Patients' anonymity was safeguarded through the assignment of pseudonyms which appeared on all written documents. The key to real names and pseudonyms, along with any other potentially identifying information, was stored on a password protected computer accessible only to the researcher. During the pilot study, the video recording of image re-creation was strictly focussed on the image, and participants' faces were not captured.

Ten of the pilot and four of the main study interviews were transcribed by the researcher. The remainder of the interview recordings were transcribed by an external company who have signed a confidentiality agreement with the university, and are experienced in undertaking transcription of confidential material such as criminal proceedings and investigations.

In order to verify the eligibility of patients to take part, and confirm details of their disease and treatment regimen, the researcher obtained an NHS Honorary Contract enabling her to access the relevant sections of their medical notes. This contract also cemented her obligation to maintain confidentiality in this respect.

4.5.3 GAINING ETHICAL APPROVAL

Both studies were reviewed and approved by a local ethics committee (see appendices 5 and 6 - letters of ethical approval). Interestingly, the requirements made by each before final authorisation given varied somewhat – even in instances where the design was identical to the previously approved pilot study. The pilot study was approved subject only to rectification of a minor error in the Health Professionals' Information Sheet. Additionally the committee recommended the inclusion of the 'Changing Faces' organisation, which provides support for people coming to terms with visible disfigurement, in the Support Services Booklet, and this was duly incorporated.

Gaining approval for the main study was somewhat more complicated. The primary objections related to the study documentation, which had not been anticipated as the information and consent forms were identical content-wise to those accepted for the pilot study, only amended in terms of the purpose and design of the study. The original consent form was replaced with the standard, less detailed, NRES-issued version; and an additional paragraph summarising the remit of ethics committees, and re-wording of a

number of sections, was required for the information sheet. A cover letter signed by the clinicians responsible for distributing information sheets also needed to be produced (something which should possibly have been predicted by the researcher). Two further stipulations, not required for pilot study, were met before the committee granted approval – agreement to inform patients' GPs of their participation in the research, and the inclusion of an academic independent of the study in the information sheet as someone prospective participants could contact for impartial information and to answer any questions.

4.5.4 TALKING ABOUT CANCER

The primary concern of the ethics committee review panels is to ensure the "safety, dignity and well-being of research participants" (National Patient Safety Agency, 2007). This refers to physical and emotional well-being, and the latter is most pertinent when researching sensitive issues such as living with cancer – an extremely personal experience which for many includes a perceived, or indeed real, threat to one's life.

There is a considerable literature around the potential difficulties and ethical considerations when carrying out qualitative research on sensitive topics, and one-to-one interviewing may present particular hazards as it is such an intimate method of inquiry (Allmark et al, 2009). Add to this the fact that participants have or are recovering from cancer, and the need for sensitivity is heightened. As Mathieson (1999, p117) explains:

> "There is a world of difference between interviewing the ill and the healthy. The ill experience physical and bodily disruption; they are at the centre of an unfolding illness trajectory… [and] must come to grips with dramatic psychosocial changes and institutional events for which they may be unprepared… the most important event in which the ill person is involved is that of negotiating the illness trajectory."

There is a moral imperative to 'do no harm', most pertinently psychological harm in qualitative research, and concerns about causing harm to people rightly justify the breadth of ethics-based literature. The fundamental issue is that talking about one's difficulties, perhaps particularly when those difficulties are ongoing, may induce distress. The research interview necessitates reflection on one's experiences and feelings, and the researcher's role is to 'probe' or encourage participants to provide as much detail as possible, and so they may think more deeply about these issues than would ordinarily be the case (Richards & Schwartz, 2002). This kind of deep reflection may raise new questions, evoke emotional responses, and influence how participants think about themselves (Entwistle, Tritter, & Calnan, 2002).

General guidelines on dealing with distress during interviews advocate promotion of participant-initiated coping strategies as well as researcher sensitivity to emotional, verbal and physical cues indicating a need to stop the interview or resist exploring particular avenues, and willingness to intervene appropriately on behalf of participants (Kavanaugh & Ayres, 1998; Allmark et al, 2009). Accordingly, participants were made aware that they were free to initiate a break, or indeed terminate the interview, at any time. The researcher was also prepared to terminate the interview if it became apparent that it was causing the participant to have particular concerns.

McIlfatrick, Sullivan, & McKenna (2006) recognised that the responsibility to mitigate harm caused by study participation should extend beyond the immediate interview however, as distress may take some time to germinate. In their study with cancer patients they formulated contingency plans in case participants required support after the interview – recommending they discuss the issues raised with others, and advising of the clinical counsellors who were available to them. Similar measures were taken when carrying out both research studies in this project. A 'support services booklet' was

constructed with details of local and national cancer charities which could provide information and support, and these were given to participants at the close of the interviews (see appendices 7 – pilot study, 8 and 9 – longitudinal study).

While the research interview may compound patients' distress about their illness in some instances, it may also have a psychologically-beneficial therapeutic value. Similarities between qualitative and therapeutic interviews, and the potential benefit of having an outsider to talk to about sensitive issues, have been widely reported in the literature (Kvale, 1996; Dickson-Swift et al, 2006). This has been the case even in the context of the most serious illnesses, for example a recent review of two qualitative studies involving 104 palliative patients and carers found that the overwhelming majority claimed taking part in the interview was a positive experience. Furthermore, there were no reports that the process had caused distress - which is not to say that participants did not become emotional or cry during interviews, simply that they did not perceive the interview as the source of their anguish (Gysels et al, 2008). Findings of positive benefit to participants are reassuring, though a recent systematic review of papers concerning ethical issues notes that there is not universal agreement as to the therapeutic benefit to participating in in-depth interviews (Allmark et al, 2009).

In terms of therapeutic value in a cancer context, Colbourne & Sque (2005) cited the climate of fear and cultural taboo which still exists around cancer as a pervasive force in their interviews with male cancer patients and their partners, and went as far as positing research interviews as an opportunity for nurse-researchers to provide emotional support to patients. The blurring of research-therapy boundaries is a contentious issue however (Dickson-Swift et al, 2006; Allmark et al, 2009), and while an inherent therapeutic value was acknowledged as a possibility, this was not a goal of the interviews in this project.

In conclusion, the harm and therapeutic scenarios are not necessarily mutually exclusive. It is possible that participants may find the opportunity to talk helpful, while at the same time some of the issues raised may cause some distress. So while plans were made to deal with situations of great distress for participants, it was noted too that this was not necessarily inevitable, and that in fact some patients may find some benefit in taking part.

4.5.5 HEAD AND NECK CANCER – UNIQUE DIFFICULTIES IN AN INTERVIEW SETTING

Researching this patient group may be fraught with distinct difficulties due to the location of their cancers and the impact of treatments - the key issue for interview research being the compromise of speech. It has been noted that such difficulties have led to the exclusion of those speech-impaired head and neck cancer patients from qualitative research, and therefore less is known about their experiences (Entwistle, Tritter, & Calnan, 2002).

Speech may be compromised in this patient group due to the presence of or treatment for laryngeal cancer, which sometimes requires removal of the voice-box (laryngectomy). In the latter instance these patients may be unable to speak at all, or may communicate with the aid of an electronic speech-generating device, or via oesophageal speech, which is a deeper, lower, raspier type of croaky sound, and can be difficult to understand.

Amongst those with the full range of head and neck cancers however two common side effects of radiotherapy to the head and neck region may impair the ability to speak. Oral mucositis, the inflammation of the mucosal lining of the mouth; and xerostomia, the

reduced production of, and thickening of, saliva can result in both difficulty speaking and pain when doing so (Sciubba & Goldenberg, 2006).

With this in mind, it was necessary to formulate some contingency plans. In the case of the non-speaking patient, it was decided that participation would still be sought, and they could provide written responses to verbal questions. This would clearly involve a deal of patience on the side of the patient, and it is recognised that the responses provided may have been less detailed than if able to communicate verbally.

In a practical sense, as mentioned previously, patients with head and neck cancer can have particular difficulties communicating due to the impact of the cancer and side effects of treatment. The comfort of these participants was ensured by being alert to difficulty or discomfort speaking, reminding patients to take a break or drink when needed, and slowing the pace of the interview down when appropriate.

4.5.6 SAFETY OF THE RESEARCHER

Ethical concerns are legitimately primarily centred on research participants, however the physical safety and psychological well-being of the researcher also warrants some consideration. Threats to the physical safety of the researcher are generally considered to be infrequent hazards outwith inherently dangerous contexts (such as prisons, areas of high crime, or where the research topic is highly political), nevertheless it is important to realistically assess the potential for violent incidents 'in the field' and install safeguards where possible (Paterson, Gregory & Thorne, 1999; Dickson-Swift et al, 2008). Therefore prior to commencing the initial (pilot) study, a researcher safety protocol was developed. This was considered particularly important given the aetiology of head and neck cancer which suggested a proportion of the interviews would take place in socially

deprived areas, and that a number of heavy alcohol drinkers or alcoholics would be included in the sample.

Interview location was regarded as the chief manipulable factor in respect of physical threats. When interviews were undertaken at participants' homes, a designated colleague – or the researcher's partner where interviews were scheduled during evenings or weekends – was notified of the address, date and time of the interview. The researcher carried a mobile telephone at all times, and telephoned said colleague/partner upon safe completion of the interview (as per Chapple, 1999). If the initial contact with the participant raised concerns about safety in a private context, it was decided interviews should only be carried out at semi-public locations. Non-residential locations available included the Maggie's Centre at Ninewells Hospital, and various meeting rooms within Ninewells and the University of Dundee which were available to pre-book or could be arranged via consultation with clinic staff.

During interviews, if a particular participant was felt to be of questionable or intimidating circumstances or emotional state, the researcher would strive to sit closest to an exit, and if possible ensure a table was situated between herself and the interviewee. Careful attention was paid to participants' tone of voice and body language, with an alertness for any indications of anger, hostility or agitation. Paterson, Gregory & Thorne (1999) concede that researchers must rely largely on intuition to identify potential threats, and advise that researchers 'trust their instincts' and respond decisively to feelings of danger by leaving the situation. And thus if at any point the researcher felt her safety was in jeopardy, she was instructed to wrap up the interview and leave – with more or less care as the situation demanded. If this proved difficult for any reason, the designated colleague/partner could be telephoned and advised she was in trouble by saying 'I'm running out of tape', which was code for 'help', and signalled the need to

contact the police. There was however no need to implement this emergency safety strategy during the execution of this research.

The potential for incurring some emotional distress due to the nature of the experiences shared by participants in qualitative research on sensitive topics has been extensively acknowledged in the literature (for example Johnson & Clarke, 2003; the work of Dickson-Swift et al, 2006, 2008, and 2009). Strategies for tackling some of the difficulties that may arise during an interview, for example a participant breaking down emotionally, were outlined by the supervision team prior to data collection. The researcher was encouraged to use her intuition and common sense in situations with participants, and to access support from her supervisors should she feel upset or distressed by any of the interviews.

4.6 CHAPTER SUMMARY

This chapter introduced the three empirical components of this project: a methodological pilot study, a meta-synthesis of qualitative work, and a larger longitudinal study. It has explained the philosophical underpinnings of this project, which was developed from a constructivist stance, and influenced by elements of Heideggerian phenomenology. The remainder of the chapter focused on the theoretical background to and design of the two 'interactive' components of the project – the pilot and longitudinal studies. The other aspect of the project, a literary exercise in the form of a metasynthesis, was exempt from the methodological concerns expressed herein, and its methods are reported separately in Chapters 6 and 7.

The focus of the two research studies was informed by Leventhal's concept of 'illness representations' (briefly revisited in this chapter), and they share a common methodological perspective. Both studies employed a qualitative design, and used semi-

structured interviewing as the mode of data collection. Reflexive and ethical concerns were also shared. This chapter has reported on these issues pertinent to both studies to avoid extensive repetition in their respective chapters. The minutiae of the study methods, specific details concerning data collection, and modes of analysis, is contained within their respective chapters – the following chapter (5) is devoted to the pilot study, and Chapters 8 and 9 to the longitudinal study.

5 ACCESSING THE HIDDEN REALM OF MENTAL IMAGES OF CANCER – A METHODOLOGICAL PILOT STUDY

The first empirical phase of this thesis was an exploratory cross-sectional pilot study which served two purposes – investigating the feasibility of the proposed methods for image re-creation, and providing some preliminary data to inform the development of a larger, subsequent research study. As illustrated in Chapter 3 of this thesis, the realm of patients' mental images of their disease, and the significance and role of these images in the broader illness experience, is hitherto a largely unexplored area, and research of this kind is in its infancy. In the absence of much published methodological evidence or debate as to the best ways of accessing these images for research purposes, it was decided to carry out a small pilot study. The main aim of this study was to investigate the acceptability and feasibility of exploring mental images, and particularly image re-creation, in the context of a research interview with our target patient population. Additionally, the pilot provided an opportunity to test out the possible inclusion of partners and health professionals in the larger study – as both parties were potentially relevant to the central focus of patients' mental images of their cancer. In addition it would provide some initial data which would inform the design of and specific research questions for the planned larger research study.

This chapter is self-contained and will recount the design, scope, and conduct of the qualitative pilot study. It will give details of the specific aims, sampling strategy, and data collection and analysis processes. The latter part of this chapter is devoted to delineation of the findings, and, following comment on the acceptability of the methods, is divided into two sections. The first reports on the nature and characteristics of patients' and partners' mental images of the cancer, while the second section pertains to health professionals' clinical use of images and their awareness that patients' may visualise their

disease. The chapter closes with a summary of the implications of these findings in terms of the direction of the larger, subsequent study.

5.1 RATIONALE AND STUDY DESIGN

5.1.1 AIMS

- To establish the most acceptable and feasible methods of accessing head & neck cancer patients' mental images of the disease.
- To yield preliminary data about the form and meaning of these images.
- To explore whether partners also visualise the disease.
- To investigate the potential role of health professionals in influencing image generation.

5.1.2 PATIENTS

The literature reviewed in Chapter 2 of this thesis outlined the significant functional and psychological difficulties head and neck cancer patients may face as a result of both the disease and the radical treatments employed to tackle it. It also described the aetiology of this group of cancers, which are most often precipitated by lifestyle choices – smoking tobacco and drinking alcohol – and are typically associated with social deprivation. The relative lack of qualitative work with these patients means their experiences and understandings of the cancer are insufficiently understood. The second part (Chapter 3) of the literature review presented evidence which suggests that patients' beliefs about their illness can influence the psychological impact of the disease, their behavioural decisions, and overall outcomes – and recent research indicates that these beliefs may be embedded within patients' mental images of the disease.

This exploratory study first seeks to establish whether head and neck cancer patients do indeed visualise their disease. It aims to answer the most basic methodological questions concerning how best to access these images, pilot testing an image re-creation tool kit devised by Harrow et al (2008). The preliminary data gleaned from a small sample of patients is analysed with view to describing the common parameters and properties of these images, their meaning or significance to the individuals, the perceived origins or influences over how patients visualise the cancer, and how they relate to specific beliefs about the disease. In short, this pilot study will explore head and neck cancer patients' mental images and the importance of these in the context of their illness beliefs and overall experiences.

5.1.3 PARTNERS

As demonstrated earlier in Chapter 2, there is significant evidence to indicate that social support can offset some of the emotional and practical burden of living with cancer. The partners of cancer patients may play a key role in providing such support, and the importance of this has been illustrated widely in the literature. In head and neck cancer, research has indicated that for head and neck cancer patients, living alone and lacking a good support network is associated with poorer quality of life, and even greater mortality (Karnell et al, 2007; Konski et al, 2006) – a finding replicated in a recent meta-analysis as pertinent to a broad range of cancers (Pinquart & Duberstein, 2010).

Cancer is generally regarded as a disease whose impact reaches beyond the patient to affect their partners and family also. Research has consistently borne out significant psychological implications for the partners of cancer patients, though its specific impact and their reaction to it may vary widely (Pitceathly & Maguire, 2003; Braun et al, 2007; Ross et al, 2010). For example the level of distress experienced at different time

points in the illness trajectory has been found to differ between patients and partners (Hodges et al, 2005).

The fact that cancer may have different psychological effects on the patient and partner suggests that their illness beliefs, understanding of, and images of the cancer may also differ. Research which has examined both patient and partner perceptions of a range of chronic illnesses has indicated that a divergence in beliefs about the illness's seriousness and consequences can be problematic (Richards et al, 2004; Benyamini, Medalion, Garfinkel 2007; Sterba & DeVillis, 2009). Not only can it compromise the ability to engage in mutually supportive activities, but given the partner's role in promoting self-care in the home and positive coping with side effects and the like, disparate understandings of the patient's condition may impact on their health-related behaviours and also the emotional impact of the disease (Weinman et al, 2000; Searle et al, 2007; Kuipers et al, 2007).

In view of the potential importance of partners in how HNC patients cope with the disease, the acknowledged impact of cancer on them, and the potential implications of divergent beliefs, it was decided to incorporate the basic question of whether partners also visualised the cancer into the study. The remit with participating partners was to identify, re-create, and explore these images and their relation to illness beliefs in the same manner as with the patients themselves.

5.1.4 HEALTH PROFESSIONALS

In terms of the origins of patients' mental images, preliminary data from a study ongoing at the University of Dundee at the time of the pilot study design - examining breast cancer patients' mental images - indicated that health professionals may exert an important influence on the construction of these. This influence appeared to manifest

through their use of visual information in interactions with patients such as scan images and the use of visual metaphors (Harrow et al, 2008). Therefore it was decided to incorporate interviews with a small number of health professionals into the study, in order to explore the use of imagery in the clinical head and neck cancer context, identify potential sources of patients' images, and reflect upon their awareness of the potential that patients interpret their disease in a visual way by constructing mental images.

5.1.5 RESEARCH QUESTIONS

1. Do patients with head and neck cancer visualise their disease, and what is the significance of mental images of the cancer?
2. What is the best way of accessing patients' mental images?
3. How acceptable is the request to re-create mental images in the context of a research interview?
4. Do patients' partners also construct mental images of the cancer, and what is their significance?
5. How are visual metaphors and images used by health care professionals when talking about head and neck cancer with patients?

5.2 DESIGN

The research design was a cross-sectional qualitative study of head and neck cancer patients and their partners (referred to forthwith as 'group 1'), and Health professionals ('group 2'). Data was collected via one-to-one semi-structured interviews. Transcripts were subject to qualitative thematic analysis. This study was approved by the Tayside Research Ethics Committee (see Appendix 5).

5.3 SAMPLING

5.3.1 STRATEGY

A purposive sample of 6 head and neck cancer patients was acquired. Purposive, or criterion-based, sampling is designed to ensure diversity in terms of the key elements pertinent to the population under scrutiny, and involves selecting participants based on decided criteria (Ritchie & Lewis, 2003, p78-79). In this case, sampling was conducted to encompass both male and female patients, of various ages, with cancer located at different sites within the head and neck, and who had undergone different treatments – factors which were considered likely to influence the individual's contribution (Marshall, 1996). All of the patients had completed their treatment bar one, who was continuing with palliative chemotherapy.

Appropriately to the qualitative design of this study, the sample was not designed to be representative of the population as a whole, but to comprise as diverse a range of patients as possible. This type of sampling does not facilitate generalisation of findings to the wider population, for example conclusions as to how many people visualise their cancer as a part of their illness experience, but it is congruent with the qualitative nature of the study, which seeks to explore the complexity and diversity of a human experience (Marshall, 1996). The features of the participants added another dimension to the analysis of the data – enabling the views and experiences of different sub-groups to be compared and contrasted (for example males versus females). Such comparisons can explicate the roots of any differences or commonalities amongst the sample, and thus ensure the sampling strategy is utilised to the fullest (Barbour, 2001).

5.3.2 INCLUSION AND EXCLUSION CRITERIA

All participants were required to be over 18 years of age. Patients had to have been diagnosed with a head and neck cancer, and partners could only participate if the patient was also taking part and they were present at the time of patient approach. health professionals were required to be currently employed in the Head and neck oncology unit, working with patients who have head and neck cancers.

People who lacked sufficient capacity to provide informed consent, and patients and partners whom clinic staff believed it would be inappropriate or untimely to approach were excluded. There was no funding available to employ translators for this study, and so non-English speaking patients and partners were also excluded.

Terminally ill patients were not barred from taking part. The sampling strategy was designed to include patients with different cancers and at different stages of disease to yield a variety of responses. Given the premise that mental images may be linked to psychological well-being, patients with advanced disease as well as those with curable disease could potentially benefit from future interventions to access and change these images. Thus patients with metastatic or terminal disease were not excluded from the study, though it was recognised that their participation could potentially be compromised by their condition.

5.3.3 PATIENT RECRUITMENT

Patients and partners were identified and initially approached through the combined ENT/Oncology Outpatients Clinic of a large teaching hospital while attending for follow-up appointments. The researcher consulted the list of patients attending the clinic – which ran one morning a week – each morning, and identified divergent cases by age, gender, and disease site/treatment by referring to the appropriate medical notes. A list of

desired patients was then passed to the clinic nurses, who invited patients to talk to the researcher about the study. The nurses informed patients there was a student from the university located in the clinic waiting area that was conducting a research study with head and neck cancer patients, and asked if they would be interested in talking to the researcher about potentially taking part. Nurses were free to use their own discretion in deciding not to approach patients whom they felt were particularly vulnerable, or for whom it would be particularly untimely, e.g. following receipt of distressing news at the present consultation. No cases of this nature were reported by the nurses.

Following consent to talk to the researcher, potential participants engaged in a conversation concerning the purpose and nature of the study, practical aspects of participating, confidentiality, and their right to decline or to withdraw at time of interview. Contact details were elicited and information sheets (see appendices 1 and 2) given out with a request to consider taking part. Follow-up was carried out via telephone – allowing for a minimum of 24 hours for the patient/partner to decide whether or not to take part, as per the ethical requirements for the study – and interviews scheduled, or reasons for declining documented, as appropriate.

Of those who spoke with the researcher and agreed to consider participation, three patients and one partner declined to take part upon follow-up. The female partner of the declining couple stated that they were 'not really into things like that', but would not expand on this further. Of the two other declining patients, one was a 70-year old woman who was five years post-treatment and visibly anxious at the initial conversation, who said she simply did not remember much about that period in her life. The final patient refusal was a 73-year old woman who was fifteen years post-diagnosis, and who appeared to be in some kind of state of extreme denial when she refused participation during the initial conversation with the researcher. This denial became

apparent as the lady claimed she'd have nothing to say as the cancer 'never happened', and she had 'never had cancer'. Appearing quite lucid and confident, she described the radiotherapy and surgery she had undergone in some detail unsolicited, while simultaneously explaining that her reason for declining to take part was not due to a reluctance to talk about it, but purely because it had never happened.

In addition to the four people who declined, one further patient initially consented to and arranged an interview with the researcher, but did not turn up, before the target sample of six patients and two partners was achieved. Interviews with consenting patients and partners were completed over a four-week period, and consent forms (see appendix 10) were discussed and signed on the day of, but prior to, the interviews. The issues pertinent to the perceived sources of their mental images were noted in order to feed the focus of the interviews with health professionals.

5.3.4 HEALTH PROFESSIONAL RECRUITMENT

Permission to carry out the study was obtained from the R&D department at the same time as ethical approval. A condition of this was endorsement by two relevant clinical professionals, and both of these also consented to taking part at the time of endorsement. This verbal consent was re-established following a further discussion of the aims of the study, provision of the information sheets (see Appendix 3), and on the day of the interviews when consent forms (see Appendix 11) were signed. Two further eligible health professionals – both nurses – were initially identified through the senior clinic nurse who was involved in recruitment planning for the study, and following a brief discussion with the researcher and the provision of information sheets, both consented to take part in interviews.

5.4 DATA COLLECTION

5.4.1 SEMI-STRUCTURED INTERVIEWS

Semi-structured one-to-one interviewing is a commonly-used method in qualitative research, and was selected as the mode of data collection. A more detailed overview of this is provided in part 4 of this chapter as it was also the method employed in the main study and this will avoid repetition. Central tenets of this type of inquiry include its exploratory nature – a 'topic guide' is used to focus the interview but does not consist of questions to be rigidly and sequentially adhered to – and the importance of asking open questions which enable participants to speak in their own words as much as possible, and to identify the issues which are important to them (Gray, 2009, p373).

Group 1, consisting of six patients and two of their partners, took part in semi-structured interviews addressing their subjective illness perceptions, feelings about and experience of the cancer, how it has impacted on their life, visualising the disease, the meaning and importance of these mental images, and the range and evolution of such images (see Appendix 12 - Patient-Partner topic guide). During the interview, participants were asked to recreate their mental images, while narrating what they were drawing and why. This 'draw and write' technique has been commonly used in a range of health research. The image re-creation process was video-recorded, and the entire interviews audio-recorded.

Interviews took place at mutually convenient locations – normally in the participants' homes. The duration varied between 47 to 185 minutes, with an average length of approximately 94 minutes. One of the couples opted to be interviewed together, and another of the patients had her sister present.

Group 2 consisted of four health professionals currently working with head and neck cancer patients. This group also took part in semi-structured interviews, addressing their awareness of and encounters with patients' images of cancer, and their own use of visual language and clinical pictures such as diagrams or scans in interactions with this patient group (see Appendix 13 - Pilot HP topic guide). Participants in this group were not asked routinely to re-create images, though they were free to sketch things in illustration of what they were saying if desired. Interviews were audio-recorded, lasted approximately 30 minutes, and were carried out in private rooms within the hospital during their normal working hours.

5.4.2 ACCESSING MENTAL IMAGES

A key research question of this pilot study was to investigate how best to access mental images of cancer. As outlined in the preceding chapter, the majority of existing research investigating mental images of disease has elicited these images through drawing. Given the exploratory nature of this study however, we wanted to make other creative mediums available to participants in order to obtain some feedback on the preferred mode of re-creation, and to facilitate the production of 3D representations for example.

5.4.2.1 THE TOOLKIT

The basis for the materials provided for image re-production was an existing toolkit developed by a colleague involved in a research project examining breast cancer patients' mental images of their disease (Harrow et al, 2008). It comprised a vast array of coloured and textured papers (from fine to felt to coarse), drawing implements, 3D materials such as pipe cleaners and plasticine, and various textured materials to provide representations of shape, texture, and consistency. A full inventory of the toolkit materials is provided in Box 1. Paints were not included as this would have required a more arduous set-up in terms of sufficient space to work in, and time to clean the brushes

and dry the picture. It was also potentially messy and this was deemed risky when interviewing people in their own homes.

Box 1 - Image re-creation toolkit materials

With their agreement, the process of image re-creation was video and audio recorded. Participants narrated the creation of their image, and were encouraged by the researcher to explore reasons for colour choice and other parameters of the image.

5.4.2.2 'I'M NOT MUCH OF AN ARTIST'

It was recognised that the request to re-create a mental image during the interview may not be welcomed by some of the participants, and doing so was not a requirement of taking part. While numerous factors may influence the response to such a request, reticence has been found to occur in those who lack confidence in their 'artistic' abilities

(Kearney & Hale, 2004). Assurances that the image re-creation was not a 'test' were made as the issue was broached.

5.5 THEMATIC ANALYSIS OF THE DATA

The audio-recordings of the interviews were transcribed verbatim. The primary purpose of the pilot study was to investigate the utility of the methods, and therefore much of the analysis was purely descriptive in order to answer the initial questions about feasibility and acceptability of the proposed image-related methods for the larger study. More extensive analysis was undertaken in respect of the research questions pertaining to the nature of mental images, illness beliefs, and patients' experiences of head and neck cancer.

In line with this objective, a basic form of thematic analysis was carried out which was drawn from the method set out by Braun & Clarke (2006). In promoting its acceptability as a stand alone 'named' method - as per Grounded Theory, for example - they cite its utility across a range of epistemological positions, and argue that all qualitative analysis involves examination of the themes or patterns evident in a set of data, and is therefore 'thematic' in nature, and that thematic analysis should be regarded as the footing upon which various modes and techniques for analysis have been developed.

Given its status as a baseline method in qualitative analysis, Braun & Clarke also argue that thematic analysis is a useful starting point for introducing the novice researcher to analysis as it facilitates development of the 'core skills' which are required to tackle different modes of qualitative analysis.

Thematic analysis was deemed to be a suitable approach to the data as it: can be applied deductively to answer specific research questions; can be used consistently within

a constructivist paradigm; and can be more or less 'deep' depending on the study aims – seeking descriptive semantic themes as opposed to more sophisticated interpretive latent themes, the former more applicable given the focus on testing the methods in this pilot study (Braun & Clarke, 2006).

A final consideration was the inexperience of the researcher, and in the same way as carrying out some pilot interviews allowed her to learn first-hand about the process, difficulties, and issues in this manner of data collection, so conducting a thematic analysis of a small number of transcripts provided invaluable insight into and experience of the analysis process prior to undertaking a more sophisticated interrogation of a larger dataset in the main study.

5.5.1 THE PROCESS OF THEMATIC ANALYSIS

Braun & Clarke (2006) describe a relatively simple six phase approach to thematic analysis, which involves a degree of floating back and forth between phases, i.e. it is not a strictly linear process. This process can be summarised as follows:

- Phase 1: Familiarising yourself with the data. Repeatedly reading the transcripts and noting down initial impressions.
- Phase 2: Generating initial codes. A systematic process of coding interesting aspects of the data and organising data into these codes.
- Phase 3: Searching for themes. Identifying initial themes and sub-themes and collating the codes/data appropriately.
- Phase 4: Reviewing themes. Considering if the themes fit with and are evident in the actual data, and reviewing the aptness of themes in reflecting the set of data by reading the transcripts again and applying additional coding if necessary. The development of thematic maps – visual representations of the network of

themes – will aid this process, and themes should be refined until satisfied they sufficiently represent the content of the data set.

- Phase 5: Defining and naming themes. Further refining and re-defining of themes to ensure they capture the essential meaning of and clearly classify each theme.
- Phase 6: Producing the report. Writing up the analysis utilising vivid exemplars from the data for each theme. There is still an element of analysis to this phase as the report is constructed to answer the research questions and tell the story of the data.

The data produced by the two groups – patients and partners, and health professionals – was analysed separately as the purpose and content of the interviews were distinctly different for each.

With respect to the images, as Kearney & Hyle (2004) contend, drawings produced by participants in qualitative research must be accompanied by a verbal explanation in order to be understood. Therefore the images created by 4 of the 6 patients and both of the partners were considered in conjunction with the recorded descriptions advanced by participants, as the purpose after all was to elicit the meaning of the images for the individual. The properties of the mental images as defined and re-created were then subject to some exploratory comparative analysis.

In practical terms, the analysis was carried out in hand-written form - using hard copies of transcripts, coding directly in the margins of the pages, diagrammatically drawing out relationships between the themes (thematic maps), and producing copious piles of paper detailing verbatim evidence for each of the different codes and themes.

5.6 FINDINGS

This part will begin with an overview of the effectiveness of the study methods in eliciting participants' images of the cancer. Subsequently the findings are segregated according to the two groups – findings pertaining to patients and partners first, then those from health professionals. The chapter will close will a summary of the key findings and the implications of these in the design of the larger study.

5.6.1 THE PRIMARY OBJECTIVE: FEASIBILITY AND ACCEPTABILITY OF METHODS

The main aim of the pilot study was to test out the proposed methods – particularly for image re-creation – in terms of feasibility and acceptability to participants. All participants who reported visualising their cancer re-created their mental images. Although most made some gesture of reluctance based on their lack of artistic ability, none refused, and once engrossed in their re-creation appeared quite happy to be doing it, and quite dedicated to making it as representative of their visualisation as possible in terms of selecting the right colour and modifying it as they went along.

The previous methods chapter described the importance of establishing a rapport with participants and building and maintaining trust throughout the interview. It was considered therefore that the subject of images of the cancer should be introduced following some initial conversation about their disease which would furnish the researcher with important contextual detail and allow some time for a good rapport to be established. Participants' spontaneous use of verbal visual descriptions were also picked up during this early period and noted for later reference. Mental images of the cancer were generally addressed during the mid or latter parts of the interview, and as this approach was successful in the first interviews, the reverse – which was less favoured from the outset given the literature on building a good research relationship and the

anticipated potential sensitivity or embarrassment of being asked to re-create such an image – was not tested.

In terms of materials, the majority chose to simply draw what they had envisaged. Representing the colour participants visualised their cancer to be was perhaps the most difficult issue in the re-creation as most patients had a very specific colour in mind, and despite offering a reasonably large range the colour desired was not always available. Jackie chose to demonstrate with plasticine alone, while Scott did so in addition to drawing. Only Graeme utilised any of the other materials – sponges – to indicate shape and texture, something which was also achieved adequately in his drawing. The verbal descriptions of the images were absolutely essential in terms of interpreting and understanding cancer, and allowed participants to show changes to how they visualised it following treatment.

All participants indicated that the representations produced were fair accounts of their mental image, and drew attention to the aspects of it which were lacking i.e. the colour not being quite right, or it being larger/smaller in real life. Participants raised no objections to the audio-recording of the interviews or the video-recording of the image re-creation, and there were no perceptible indications that the latter inhibited participants' drawings.

Despite the provision of an extensive range of materials for participants to choose from, the fact that the majority of them elected simply to sketch their cancer indicated that drawing materials may in fact have been sufficient for image re-creation. Where characteristics could not actually be represented with the available materials – such as texture – participants provided detailed verbal description, which suggests that if the

tool kit is in fact scaled down for the later study this need not necessarily impinge on the quality or depth of the investigation.

5.6.2 GROUP 1: PATIENTS AND PARTNERS

Patient and partner interviews concentrated on their understanding of the cancer and treatments, and the issue of whether or not they had a mental image of the cancer. This section will detail the findings as they relate to the research questions set out earlier in this chapter, concerning the existence, characteristics, nature, and origins of such mental images.

5.6.2.1 SAMPLE CHARACTERISTICS - PATIENTS AND PARTNERS

Table 6 – Patients and partners demographic and disease details

	Marital Status	**Disease Site**	**Treatment**	**Treatment Stage**
Michelle (F, 47)	Married (to Robert)	N/A - Partner	-	-
Robert (M, 50)	Married (to Michelle)	Parotid gland, metastases to lung and liver	- Radiotherapy - Chemotherapy - Surgery	Currently undergoing chemotherapy
Sally (F, 64)	Divorced	Tongue + lymph nodes	- Radiotherapy - Chemotherapy - Surgery	2 years post-treatment
Craig (M, 82)	Widowed	Larynx	- Radiotherapy - Surgery (laryngectomy)	11 years post-treatment
Scott (M, 62)	Married	Larynx	- Radiotherapy	1 year post-treatment
Graeme (M, 53)	Married (to Jackie)	Nasal cavity	- Radiotherapy - Surgery	2 months post-treatment
Jackie (F, 51)	Married (to Graeme)	N/A - Partner	-	-
Kathy (F, 47)	Single	Tonsils + lymph nodes	- Radiotherapy - Surgery (neck dissection)	6 months post-treatment

5.6.2.2 VISUALISING CANCER

Do HNC patients visualise their cancer?

Four of the six HNC patients interviewed – Robert, Scott, Graeme and Kathy – described visualising their cancer. Craig, who was – perhaps notably – eleven years post-treatment, reported never at all considering what his cancer looked like.

Sally also said thoughts of this kind never featured throughout her experience, though upon thinking about it at interview she conjured a basic image comprising two characteristics – colour and texture/consistency – of which she was very certain – though imagining her cancer was not a natural part of her illness experience.

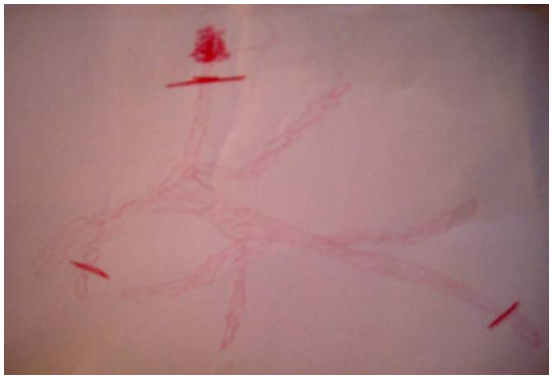
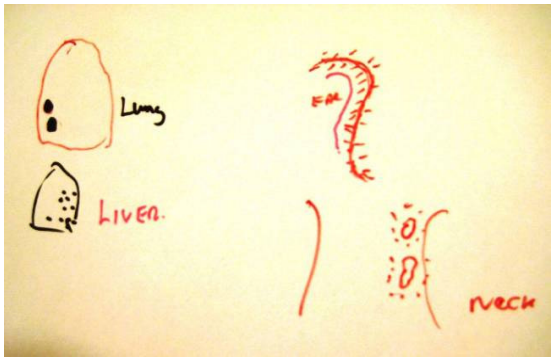
Do partners too construct a mental image?

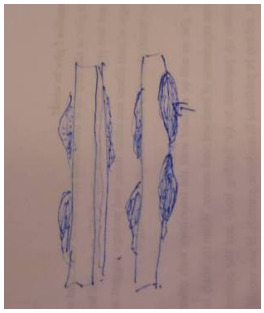
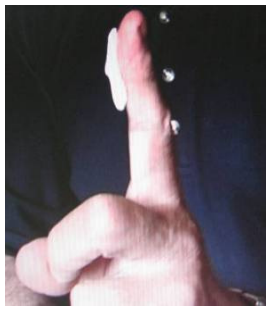
Both of the female partners interviewed described visualising their husband's cancer, and cited the function of their mental images as enabling understanding of what was there, and what needed to be dealt with. Interestingly, neither pair of partners had ever discussed their mental images of the cancer, though aspects of Michelle and Robert's concurred, and Graeme and Jackie's were startlingly similar.

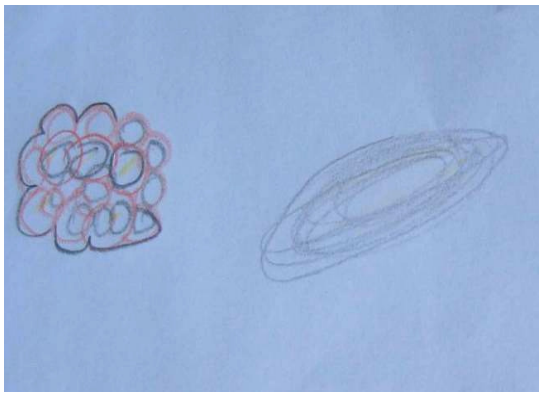
5.6.2.3 PARTICIPANTS' IMAGES – CASE SYNOPSES

The images produced by those patients and partners who did visualize their/their partner's cancer shared very few unifying features. In order to illustrate the uniqueness of each individual's conception of the cancer more fully, and facilitated by the small sample size, a synopsis of each participant's mental image and the pertinent features of these is presented in table 7 below.

Table 7 - Synopses of the images produced by patient and partner participants

Image produced and its pertinent features	
#1 Michelle – drawing of partner's cancer  - Shape: long and thin, and 'squishy' in texture, with tendrils which were spreading out in different directions. - Very clear notion of colour: "I see this – I suppose in stark contrast to… blood colours and things like that. It's pale, pale… pink, the palest pink." [p10]	- Characterised the cancer as 'pernicious': "…tendrilling out… in all sorts of different directions, and curling round things… and just creeping and invasive" [p15] - Post-surgery most of the cancer was removed, but three 'bits' remain – shown where chopped by the dark pink lines on her drawing. - Two of these bits are simply 'chopped', no longer spreading or tendrilling out, just sitting there 'chopped'; while the third bit (in dark pink) is enlarging.
#2 Robert – own cancer and metastases  [The red flecks around the ear and neck tumours are not part of the cancer but denote its 'inflammation'] - Distinguished between the character of the cancer at his neck and ear, and the cancer in his lung and liver.	- The tumour behind his ear: "I just thought it was like a big, like a runny sausage or something down your neck, and they just cut me open and took this long bit of… nine centimetre bit of, er, flesh out." [p42] - Neck and ear cancer colour: "Just a more er, like fiery reddy colour than… the colour of your skin… more fierier, more red." [p43] - The metastases to his lung and liver, which he termed 'spots' and 'seedlings', he imagined simply as 'wee black spots', devoid of any other characteristics.

#3 Scott – own larynx cancer   Drawing of the cancer on the vocal cords. Plasticine represents cancer on vocal cord. - Described the cancer as akin to a lump of bread dough that had been left too long. - The cancer itself was growing, embedding itself into, and protruding in the form of a lump from, his vocal cord.	- Derived primarily from the HP's description of the cancer and his own beliefs about the nature of cancer itself: "He said 'something white'. And then after, when I think about it – what did it look like, really – and you think cancerous and you think yeuch you know, and you think festering and… and I, I think about bread dough that's been left too long… right, that's gone all a dirty grey colour." [p39] - The texture was exactly like bread dough – 'squishy, squashy'.
#4 Graeme – two images of own cancer   Two depictions of image A. Left: the shape of the vision; Right: the vision shape and texture. - Described two images, but re-created image A only. - Image A – a metaphorical vision of the cancer: a 'ghoulish' being, with fiercely jagged edges, screaming as it was vanquished by the radiotherapy:	… - "This sort of jagged, reddish-brownish thing which was screaming, which was getting cast aside – as if the disease was getting pulled out, thrown away" [p91] - Image B - a 'realistic' image of it: described in great depth, and likened extensively to partner Jackie's. Described as a dark, round, 'swollen circle', the size and shape of an old penny or half a crown, which was fluid-filled and jellyfish-like in texture. - The colour was a dull, dark, purpley/brownish and very specific in his mind.

#5 Jackie – Representation of partner's cancer  Left: Original image of her partner's cancer. Right: What was left after the 'de-bulking' operation. Jackie's image responded to her understanding of Graeme's treatment. Originally the tumour was a flat, round, and red, with slightly ragged, imperfect edges.	- Colour reflected the nature of the cancer: "…we associate things that are not very nice or sore with red… it must be red and angry" [p76] - Described as: "…a piece of play-doh flattened out… I'm thinking to myself well he was still able to breathe so it couldn't have been too deep so I'm thinking of it being flat against the roof of whatever is above there [indicates nose] …on top of his palate somewhere, going on to the soft palate." [p77] - Post-surgery the cancer was no longer round, but 'crescent-moon shaped'.
#6 Kathy – own cancer and lymph gland  Left: the cancer, and Right: the lymph gland. - Able to actually see and feel the cancer located on her tonsil (unique in this sample). - Texture of the cancerous tissue: 'brick hard' and 'rough'. - 'Honeycomb'-shaped – a crowd of red circles with yellow pus at their centres, which she imagined were 'turning black':	… - "Once they telt me it was cancer, that's when I started visualising it turning black and pussy… it's dying, it's – I dinnae ken it's, it's turning black… its eating a'thing awa' at the back of my throat." [p73] - Described the how the cancer grew bigger: "…just other bits of cancer just joining on… ken like a chain." [p69] - Meantime the lymph gland was not getting bigger, but turning blacker and filling with pus denoted by the yellow at the centre of the drawing.

Only two patient participants reported never visualising their cancer. Craig was the eldest of the sample aged 82 years and was also the furthest post-treatment (at eleven years beyond), and poor recall, or a lack of desire to recall, may have been factors in this – unless he simply never did imagine it. The second non-visualiser was Sally, who said thoughts of what the cancer was never occurred to her while she was going through it. Thinking about it during the interview however she did give an account of what it looked like, describing it as 'black, hard and blob-like' [p72-74], and claiming to be very certain of these attributes. The colour black represented the 'negative' nature of the disease, and though her neck felt of only soft tissue, the palpable lump there suggested hardness to her: "Well how I think that was cause my neck wasnae hard – but cause it was a lump, I thought it would be hard inside ken". Notably Sally referred to the characteristics of the swollen lymph nodes in her neck when describing her cancer, rather than the actual cancer which was located at the base of her tongue.

5.6.2.4 WHAT ARE THE COMMON PROPERTIES, PARAMETERS AND CHARACTERISTICS OF THESE IMAGES?

In order to delineate the nature of participants' mental images of the cancer, they were first scrutinised simply in terms of content. Three key properties were identified in this respect – colour, shape, and texture. Two types of image were reported (realistic or literal and figurative), and discussion with participants also enabled the stability or durability of these mental images to be ascertained. Additionally, some participants conveyed the perceived behaviour of the cancer (its action within the body), and the perceived sources of specific images were also explicated. The variance in these common characteristics is shown in table 8 below.

Table 8 - Parameters of patients' and partners reported images

	Colour	Shape	Texture	Stability	Behaviour	Sources
Michelle Realistic image	Pale pink	Like a piece of seaweed	Squishy and thin	Enduring but responded to treatment	Spreading Then chopped but growing	- HPs' descriptions - Anatomical knowledge - Symptoms experienced
Robert Realistic image	Fiery red And black	Sausage-shaped And spots	Slimy Runny sausage	Enduring	None indicated	- HPs' descriptions - Symptoms experienced
Scott Realistic image	Dirty grey	Like a piece of Bread dough	Squishy, Squashy, soft	Enduring	Growing	- HPs descriptions - Symptoms experienced
Graeme Image A – Figurative	Reddish/ Brownish	Jagged and ghoul-like	N/A	A one-off experience	N/A	- Understanding of radiotherapy
Graeme Image B - Realistic	Purpley/ Brownish	Round swollen circle	Fluid-filled	Enduring	None indicated	- HPs descriptions - Symptoms experienced - Previous experience
Jackie Realistic image	Red	Flattish and circular	Like plasticine	Enduring but responded to treatment	None indicated	- HPs descriptions - Symptoms experienced
Kathy Realistic image	Black and yellow	Honeycomb and an oval lump	Hard and rough, with pus	Enduring	Growing – accumulating more cancer cells and pus. Turning blacker.	- What she could see and feel - Beliefs about cancer

5.6.2.4.1 COLOUR

Colour was one of the earliest-cited image characteristics, and one which participants had imagined very vividly and precisely. Reasons behind colour choice included an emotional meaning, or an intellectual association, or the colour it had been described as by health professionals.

The underlying factors behind colour choice did not always appear to be close to the surface of participants' minds, though most did identify a covert source. An emotional meaning behind the colour black for Kathy:

> "… Soon as they told me I had cancer that's what I visualised, started to visualise… …Yeah, black is a sign of death, it's associated with death isn't it?… …That's why I, I was thinking [that]." [Kathy p75]

The influence of prior knowledge on Michelle – a trained nurse:

> "…because, possibly… you know it's, it's as opposed to if you cut a body open and it's, and it's dark, and it's deep, and I know that there are organs that are pale grey and they're this and they're that, but I see this – I suppose in stark contrast to… blood colours and things like that. It's pale, pale… pink, the palest pink." [Michelle p10]

Scott relating how his initial image was white because the consultant described it that way:

> "He said 'something white'… That's my mental image of what cancer looks like. If he'd have said it was something red, or it was something purple or something black or whatever – I might have had a different picture of it." [Scott p40]

5.6.2.4.2 SHAPE

Shape was a second key characteristic, which related primarily to the location, size and symptoms of the cancer. The is exemplified well in the case of partners Graeme and Jackie who, independently of each other, visualised the former's cancer as flattish shape-wise.

> "…I thought gosh it's big – and I kind of imagined a piece of play-doh flattened out… I'm thinking to myself well he was still able to breathe so it couldn't have been too deep so I'm thinking of it being flat against the roof of whatever is above there [indicates nose] …on top of his palate somewhere, going on to the soft palate." [Jackie p77]

Both cite the consultant's description of size – 3-4cm in diameter – along with their perception of the capacity of the nasal cavity as rather limited, as informing their belief that the cancer itself must have been relatively flat in order to fit. This was reinforced by the knowledge that Graeme could still breathe through his nasal passages, and therefore it could not have been protruding so much in the form of a lump.

Robert's image of the shape of the tumour by his ear also reflects this:

> "I just thought it was like a big, like a runny sausage or something down your neck, and they just cut me open and took this long bit of… nine centimetre bit of, er, flesh out" [Robert p42]

Although in this case the shape is not informed by symptoms, but by his understanding of his surgery.

5.6.2.4.3 TEXTURE

Texture was also considered by all participants, and often mimicked the real-life texture of objects they likened their cancer to in other respects. For example Michelle described the shape of her partner's cancer as 'creeping… spreading… [shaped] like a piece of seaweed' – and the texture as 'squishy and thin'. Scott likened his initially in colour to a 'dirty grey lump of bread dough' and later the texture as 'squishy, squashy… soft' and exactly like bread dough.

This poses the question of, in the absence of visible indicators of texture, where the texture of the chosen simile 'object' appears to be adopted in lieu – how important or salient is this feature in participants' mental images?

This was not true for all participants however. Graeme formulated a clear idea of the texture or consistency of his cancer, based on the symptoms he experienced.

> "You see up until that point, em, well you know, before I was operated on, if I lay on one side I could breathe, if I went over to the other side it kind of blocked my nasal passages. So I kind of had this vision of this, you know sort of…'thing' - kind of jelly-like, moving over or something like that, you know." [Graeme p66]

Also described as 'jellyfish-like', and a balloon partially-inflated with water, the soft texture of Graeme's image allowed it the fluidity required for it to bulge sufficiently and cause the blocking of his nasal passage that he experienced when lying on his right side.

Because Kathy's cancer was located on her tonsil, she had a – unique in this sample - opportunity to actually feel the tissue there which felt 'brick hard' and rough. This

experience, in addition to feeling the palpable lump in her neck, then informed her impression of the texture of her lymph gland as hard also.

> "And the one in the neck was just, just a hard thing like that wi' just a, a mass of black." [Kathy p68]

5.6.2.4.4 IMAGE STABILITY

All participants considered their own mental image of the cancer to be an enduring one, although elements of it developed at later time points throughout their experience. Michelle for example had always envisioned her partner's cancer as creeping and spreading in different directions, but it was upon receiving the surgeon's pre-operative explanation that the spreading tendrils took on the facet of actually winding themselves around nerves

> "…I started thinking 'right it's wound round his carotid; it's-, it's invaded - nerves', you know it's done this – wound round nerves they're-, they're gonna have to… you know cut, cut this away and, hopefully leave the nerve intact." [Michelle p19]

In addition, the original, enduring mental image of the cancer was responsive to the treatments undergone in some cases, as per Jackie, for whom the shape changed to reflect her husband's surgery, and indicate what remained for the radiotherapy to 'deal with'

> "I thought well he managed to get a lot of that away so in a way it's looking different now, because it's not gonna be round and flat – it's going to maybe be sort of almost like, crescent-moon shaped!" [Jackie p78]

All bar one of the participants appeared to view their mental image as peculiar to their own particular cancer. Scott however, who had never imagined cancer before his own diagnosis, despite an extensive history of familial cancer, now considers his image to be representative of all cancerous tissue, which suggests it may endure beyond his own experience, to that of others.

> "That's my mental image of what cancer looks like – irrespective of whether it was on my throat or whether it was breast cancer or, bowel cancer, or wherever. That's my mental image of what a cancerous tissue looks like. Maybe it's not – but this, this is what's in my mind. What I say is – ah yeah, when I look at it I say 'yeah that's cancer'." [Scott p41]

5.6.2.4.5 NATURE

The nature of the mental images reported could be characterised as 'realistic' or anatomically-based. That is not to say that they were necessarily anatomically correct, but that they fit with participants' understandings of what was going on inside their own and their partner's bodies. While only Robert and Scott actually drew the cancer within its anatomical context, all were able describe the precise location of the cancer.

The most eminent purpose of participants' mental images was as a tool to enable understanding of the disease and its progress – hence their 'realistic' bent. The manner in which some participants assimilated the receipt of new pieces of information, and the administration of treatment, into their original mental images too supports this notion.

The exception to this was Graeme who, in addition to a realistic mental image of his cancer, reported having a one-off experience of a figurative (metaphorical) image of

his cancer. This was unique amongst this group of participants, and is outlined later in this chapter.

5.6.2.4.6 BEHAVIOUR

The perceived action or behaviour of the cancer was not always apparent in participants' images. Graeme, Jackie, and Robert describe imagining the cancer as simply being there, not necessarily doing anything, which is perhaps surprising in the case of Robert who had had metastatic disease in his lung and liver. Scott, Kathy and Michelle however describe the behaviour of the cancer in ways indicative of their perceptions of the nature of cancer.

Michelle described Robert's cancer as 'spreading' – a reasonable description of it metastasising by its continuous 'tendrilling out' in different directions. But she also characterised it as 'creeping' and 'pernicious' which appears to be reflective of it as stealthily concealed, while spreading gradually and harmfully throughout her partner's body, so that by the time it was diagnosed its total length was 27cm.

This interpretation is supported by the change in the behaviour of the cancer she reports post-surgically – of the three 'bits' which remain – two of which are just there, while the third is growing, but is no longer spreading or creeping

> "And, they're still chopped off and I don't see them as tendrils anymore, it's maybe like – just chopped off 'bits'. And, when they said after the scan that one had... grown... I don't know how I think about that one. That it's just grown, but it's not tendrilly anymore. It's, it's now... bigger. But not spreading, but now it's just... bigger. …Before I had it, running around attaching itself to things – now I'm not – this thing is bigger, and it's causing a lump so it's getting bigger, but in my head…

> I don't see it, tendrilling towards his brain or tendrilling towards his spinal column, I just see it: bigger." [Michelle p10-11]

For Scott the behaviour of the cancer was significant to the extent that it modified the colour of his mental image from white to dirty grey, as it was 'festering' – rotting or decaying – and so the more akin to greying bread dough which was going 'off'.

Kathy described her cancer as 'eating away' at her healthy tissue – represented visually by it turning blacker. The cancer at her tonsil was also getting bigger, not growing from the inside, but being built up by the continual 'mass gathering up' of cancer cells.

> "…And this one just things joining on, just like a chain just joining on, and getting bigger all the time……like a honeycomb but just getting bigger and bigger and bigger, ken things just joining on to it." [Kathy p70]

She imagined her cancerous lymph gland's behaviour differently however, not spreading or growing, but just turning progressively blacker and filling up with pus.

5.6.2.5 WHAT ARE THE PERCEIVED ORIGINS OF THE IMAGES?

Health professionals appeared to play a critical role in shaping patients' and partners' mental images of the cancer. Their influence was evident in each case in this sample, affecting various different aspects of the images, and this influence was frequently cited by participants. Descriptions of the cancer - in terms of size or colour - were one facet of this. The impact of the stated size on the flattish shape Graeme and Jackie's images took on has already been outlined. Scott clearly articulated that his dirty grey bread dough image originated as white, as per the consultant's description, and was then modified via his own beliefs regarding its behaviour/character to become dirty grey. Thus the impact

of HPs' language was not necessarily as straightforward as size equating to size, white to white, but could be in the form of size to shape, and white as the 'initial' colour.

The ways in which radiotherapy and surgery were perceived was another influence over mental image construction. Several of the participants' images were responsive to the treatments as they understood them, and participants' understandings of their treatments appeared to be heavily embedded in visual concepts conveyed in the language used by HPs, and it was in these terms that the treatments were discussed during the interviews . This influence was especially evident in Michelle's account, where both aspects of the shape, and the pre- and post-operative behaviour of the cancer were informed by information received from HPs.

> "I think again I, I was influenced by the-, the pre-amble, before the operation…it was at that stage that it was… that I started thinking 'right it's wound round his carotid; it's-, it's invaded – nerves', you know it's done this – wound round nerves they're-, they're gonna have to… you know… cut this away and, hopefully leave the nerve intact" [Michelle p19]

Finally, the use of visual language which conveys an image also seemed relevant to patients' mental images. For example Graeme and Jackie, on discussing their remarkably similar mental images, concurred that clinicians' use of the word 'melanoma' was partly involved in the construction of the flat, round shape of their images as it evoked the image of a 'flat brown thing' – a mole. However, the mental images produced were by no means the linear result of the – albeit extensive – influence of information imparted by HPs.

The symptoms experienced by the patient were another contributory factor in image production, as exemplified earlier in Graeme's account of arriving at a jellyfish-like texture of his image due to the blocking of his nasal passage when lying on one side which indicated a degree of fluidity for him. Another example is Scott's understanding of his loss of voice influencing his notion of the cancer protruding in the form of a lump from his vocal cord.

> "And the reason, the reason my voice was going, was because the cancer wasn't allowing the cords to vibrate… cause that's how your voice works… because the cancer was, just like – for all the world like, sticking a piece of plasticine or something on your finger and, and then trying to get it to move." [Scott p42]

Individuals' beliefs about the disease and treatment were also apparent in how they visualised the cancer. Robert, who had a strong family history of cancer, and who believed his disease to be solely of genetic origin, described his cancer as a 'bit of flesh' and 'just a bit of skin', the discolouration of which was the only distinguishing factor from normal tissue. The cancer was a part of his own body, produced from within as a result of a 'bad gene', and this causal belief appears to be borne out in his description of the tissue.

For Kathy, who was able to actually see the cancer on her tonsil and its red and yellow colour, her belief that the inevitable consequence of cancer was death was borne out in her mental image of the cancer as 'turning black', which she said symbolised the 'diseased and dying' tissue, and death.

Finally, in the one non-realistic mental image reported in this sample, Graeme's vision of the cancer being cast out of his body reflected his understanding of the radiotherapy he

was undergoing, and his beliefs in the efficacy of this treatment in curing his illness (Graeme's experience is outlined in the subsequent section).

Additionally there was evidence of previous experience or knowledge pertaining to anatomy and cancer exerting a, somewhat lesser, influence. In the case of Michelle, whose nursing experience had no enormous bearing on how she visualised her partner's cancer, nonetheless explained its colour in terms of a contrast to the normal internal bodily colours. Whilst Graeme cited having seen a purple-coloured facial tumour prior to his diagnosis as one factor in the construction of the colour of his own image.

5.6.2.6 A VISION – A UNIQUE EXPERIENCE

Graeme was the only participant to report a non-realistic, figurative mental image of his cancer, in the form of a vision he had experienced, which represented the cancer being cast from his body, into oblivion. He described this vision vividly.

> "…It was almost like there was another sort of em, funny, spooky being inside me – which was getting cast aside. Em, I've never spoken about this actually… the best way to describe it visually would be… a kind of ghoul, with jagged - red jagged spikes all round about it…and kind of screaming as it was getting cast away, into nothing. I sort of em had this sort of vision – but just once, like that." [p62]
>
> "…I don't know why I had that vision – I don't usually have visions or anything like that, but one morning I had this vision, of, of this thing, em… the way I think about it is that I had that vision because that was it out of my body…… it was almost like it was an evil part of me that was getting ripped out, in a way you know, sort of thing, cast aside… I just woke up and I had this sort of vision in my head." [p63]

"… And I've, I've never ever thought about anything like that before, and I haven't thought anything since, like that you know." [p65]

"…I wouldn't say it was spooky or anything like that, you know I didn't feel spooked by it … it was something that I hoped had actually happened, you know it had actually got rid of it, you know." [p96]

This single vision occurred when he was approximately two-thirds of the way through his radiotherapy. And the timing of this experience was significant as it revealed its origins in his understanding of his treatment – it was the point at which he believed the cancer would have been destroyed, believing the remainder of the treatment to be an insurance against any cells which had escaped. Although in fact this was not the case, for Graeme the experience left him with a sense of hope and optimism that he was rid of his cancer.

5.6.2.7 SUMMARY FINDINGS GROUP 1: PATIENTS AND PARTNERS

The results of this pilot study affirmed that the Harrow et al (2008) approach to externalising mental images can be implemented acceptably with head and neck cancer patients, despite the typical demographic differences between this group and breast cancer patients with whom it was first trialled. Most of these participants elected to simply draw their cancer, and while the toolkit was limited in terms of the colours available this did not seem to produce conformity amongst participants – that is patients willingly disclosed shortcomings of the materials such as this and elucidated the discrepancies between the image produced and their actual mental image, rather than the materials available appearing to constrain the images reported. All of those patients who reported having an image of the cancer agreed to re-create it, and the timing of re-creation during the latter part of the interview, allowing the researcher and participant to first develop a relationship before introducing what was considered a somewhat 'embarrassing' exercise, appeared to be a suitable approach. In summary,

the pilot study suggested the proposed methods for externalising patients' images would be both acceptable to patients and feasible in the context of a research interview for the later study.

This initial study also demonstrated that visualising the disease can be an important part of the illness experience for head and neck cancer patients and their partners, who may develop a mental image of the cancer as part of their broader understanding of it. The majority of mental images reported by participants were 'realistic' in nature – in terms of the individual's comprehension of the cancer and its anatomical context – and their purpose seemed to be to facilitate understanding of 'what is going on'. The most salient characteristics of such images were colour and shape, while specifics pertaining to texture and behaviour of the cancer were also noted. A complex array of factors influenced the construction of images of the cancer, and participants were often aware of where their peculiar notions of the cancer came from and would verbalise this. The role of health professionals was emphasised, who influenced aspects of participants' mental images through their use of visual language and evocative terminology when discussing the cancer and treatments. Other influences included the symptoms experienced, beliefs about the disease and treatments, and previous knowledge of anatomy/cancer. Participants reported their mental images of the disease to be stable and enduring, rather than having generated multiple different images, although they may respond to the receipt of new information and how patients envisioned the impact of treatments.

The implications of these findings in terms of the later study are outlined in the closing part of this chapter. Meanwhile the following section will relay the findings pertinent to group two, the health professional participants.

5.6.3 GROUP 2: HEALTH PROFESSIONALS

Interviews with health professionals concentrated on their use of clinical images and vivid visual language in interactions with head and neck cancer patients, and their awareness and experiences of patients' mental images of the disease. This section will report on how both actual (pictorial) images and images conveyed through the use of visual language are used in a clinical setting, and the apparent hidden nature of patients' mental images of the cancer.

5.6.3.1 SAMPLE CHARACTERISTICS

Four HNC health professionals participated in the study. The sample included two female ENT clinic nurses – Pam and Phyllis – who have 3.5 years and 16 years experience with HNC patients respectively. Two male consultants completed the sample – Cameron is a clinical oncologist working with HNC patients for 5.5 years, and Michael is a lead consultant surgeon in HNC services, with 11 years experience with this patient group.

5.6.3.2 USE OF IMAGES IN A CLINICAL CONTEXT

Part of the rationale for including health professionals in the pilot study was to gain some insight into the ways in which images are used during interactions with HNC patients, and therefore may act as potential influences or sources of patients' own mental images. The nurses had little cause to employ images during their contacts with patients. However both the surgeon and the oncologist identified various images to which patients may be exposed in the course of their relationship, explicated in the table below.

Table 9 - Clinical use of images

Image Type	Context of Exposure
'Live' internal images during 'scoping'	Routine inspection of the upper aero-digestive tract at appointments involves insertion of a small camera which feeds images to a TV-sized monitor.
HP-drawn anatomical sketches	Often created to keep a clinical record of cancer size/location, can also be used to aid explanation of the cancer/treatment sites.
MRI or CT scans	Patients may be asked if they would like to see their scans.
Chest x-rays	Individual patients may be shown these if the cancer has spread to their lungs.
Sketches or diagrams	May be present in routinely provided patient information booklets.
Standard anatomical diagrams	Sometimes used when explaining surgery – e.g. laryngectomy.

Of the participants, the surgeon reported most frequent use of images with HNC patients in his role explaining the diagnosis and location of the cancer to patients, and to demystify some of the symptoms they were experiencing. This often took the form of sketches, which would then be stored in the patient's notes and serve as a record for the HPs to revisit subsequently.

> "To me a little sketch and a diagram is often far more useful than a whole lot of words to describe this sort of thing - in er, in the clinical context of a lot of these cancers cause you can actually draw exactly where it is and it has three dimensions and, explain to people why they're husky or why they can't swallow properly on the basis of where the problem is." [Michael, p5]

As indicated in the quote above, Michael felt head and neck cancers lend themselves well to this in his practice as the anatomical sites can be easily and realistically reproduced in simple drawings.

By contrast, and perhaps due to the different nature of his role clinically (explaining treatments as his primary concern as opposed to explaining the cancer), the oncologist reported only minimal use of imagery with HNC patients compared to other cancer groups. In his opinion HNCs, by virtue of their location, demanded little use of visual aids in order to relate planned treatments to patents.

> "I treat different sites of disease, it's um – it would be unusual for me to… use a diagram in head and neck for some reason. Mainly because you can point it out and say 'I'm gonna treat you there, and I'll treat that'. Um, though certainly um, in my gynae practice I'll often – you know they'll say 'where is my cancer' and I'll draw a picture of a pelvis and, you know explain where I'm treating and why I'm treating it… …Um, so that, certainly my experience is that I use diagrams much more commonly in my gynae practice than I do in head and neck. Then again, that's just maybe because as I say in head and neck it's easier to, to sort of point to a tonsil or a neck node and say that's what I'm gonna treat." [Cameron, p11]

The general perception was that the desire for this kind of visual information was present in only the minority of HNC patients however, in particular with regard to 'real-life' scans or monitor images during scoping procedures.

> "Or it's, you know they can actually see on the monitors in the rooms, if they like, for the – the initial consultation if they feel, they have that…… um, but not many of them do ask [to see what's on the monitor], not at the initial consultation." [Phyllis, p9]

> "We have like the odd patient who, when you're scoping them, will maybe want to look at the screen. A lot of them don't – they don't want to see what they look like

inside. I don't know if that's anything related to the cancer though, because some patients – like rhinology patients – and we're maybe looking in their nose and it will be something completely benign and, again, it comes up on the screen and doctor will say to them you can have a look if you want and they're – oh no, don' t want to look, so I don't know if that's necessarily to do with the cancer, but you get somebody who might be interested in looking at the screen and some who aren't." [Pam, p8]

"Um, it's much more common for, for example my cervical cancer patients to want to have a look at their scans and to see their post-treatment scan and, you know. Um, much less so with, with head and neck." [Cameron, p17]

Indeed the surgeon who reported frequently offering patients the chance to see their scans concurred with this view, adding that it is difficult to demarcate which 'type' of patients do or do not want to be shown their scans etc

"Er, I don't think you could easily categorise who do and who doesn't, I mean it's usually, em… it's, it's – I don't know whether, I don't think you could sort of break it down in socio-economic sort of class or reasons because you get huge variation in that, so you get some people who you would think you know they're from a sort of high social, socio-economic class, would want to know every sort of bit of information about something – and they don't want to know. And then you've got other folk that are you know, just you know…pretty deprived background, who want to know everything so, it's difficult to put them into categories, I don't know – it's so individual you know." [Michael, p8]

5.6.3.3 CLINICAL USE OF VISUAL LANGUAGE

All participating health professionals' accounts were consistent regarding the purposeful avoidance of euphemisms or jargon when referring to the cancer itself. Not necessarily unit policy, the individuals taking part strongly felt it important to be direct with patients and counteract any potential ambiguity over the diagnosis by citing 'cancer' specifically.

> "They'll say the word cancer rather than tumour, lump… … It can be confusing, because you can get tumours that are benign, you know. You just don't want any confusion there. You want to tell them it's benign or it's cancerous, so it's better to use the word if its cancer rather than lump or tumour." [Pam, p7]

> "…And I use the term 'cancer' – I don't use 'lump', 'neoplasm', 'tumour', 'growth' – none of those. Um, it's straight in with the word 'cancer' right at the start." [Michael, p10]

And the entity of cancer itself was perceived as something that was understood at a basic level by all – a disease everyone has heard of – and therefore required little description in terms of what it actually or physically is.

> "I, I think when you use the, the cancer word, I think the vast majority of people know, know what it is… …Now if you were to ask them to then explain 'what does cancer mean to you?' – I think you'd get a whole spectrum of answers. But everybody's got this sort of nebulous concept of a, of this nasty disease that can kill you." [Cameron, p13]

The only physical characteristics usually conveyed to patients were anatomical location and size, though the colour of the affected area or cancer may be commented on

during/following inspections of the area – at any time throughout the trajectory – when HPs have direct sight of it.

> "Um… often if you see a little white patch that you think is just sort of superficial leukoplakia or something like that, you'll say 'well you've got a bit of a white patch there I don't think it's anything to worry about, keep an eye on it'." [Cameron, p16]

> "Yep, yeah, yeah – 'you've got a white patch' or 'a redness', the colouration of things I use quite a lot too. I had somebody yesterday who I saw in Fife where, they were very hoarse, and I had a look at their voice box and just the – I think the way I described it to them I said … …'there's just a little bit of redness, it's a little bit more red on the one side than the other, and because of that difference I'd have a wee suspicion that we might need to get a biopsy because this might be something cancerous'. So that colour usage and, you know giving them some indication of just what size you're dealing with." [Michael, p15]

The use of visual language in a figurative sense (i.e non-literally, involving simile or metaphor) appeared to be largely confined to describing the size of the cancer (or occasionally the structure/functioning of the larynx which could be related to 'a pair of scissors'). Though the oncologist said this was more frequent in his contact with other types of cancer patients whose cancer was concealed internally and could not be readily felt or seen, the surgeon who conveyed the initial diagnosis claimed to use these analogies more commonly.

> "I mean quite often you'd use you know 'the size of a pea' or you know, I've used 'the size of an orange' sometimes when somebody's got a big lump in their neck.

> You know that type of thing so, yeah you do try and – 'the size of a golf ball', 'the size of a chicken egg' – I don't know whether, but that does come in." [Michael, p14]

Interestingly, the nurses were apparently unaware of the use of visual language in the form of metaphors or similes - location and size of the cancer was routinely commented on in the clinic, but it was not described visually by HPs. And the nurses themselves had no recourse to visual language in their interactions with patients.

Indeed the transcripts revealed little informal use of visual language by HPs other than when asked for explicit examples, however a notable exception was Phyllis who, during discussion of the nature of the patient group and information provision commented:

> "On, on their throat – it's like getting sunburn inside with radiotherapy, so it's quite, yeah it's quite severe. So they'll say, they'll say 'well you know you can have a pint if you want but try and keep off the spirits." [Phyllis, p17]

> "And radiotherapy I have seen and so, and I could go through that, and the leaflet goes through everything about making the mask, and how they have to be specific about where the beam goes and et cetera and that." [Phyllis, p11]

These excerpts indicate how images embedded in visual language may be related to patients without HPs being necessarily sensitive to their use.

5.6.3.4 EXPERIENCE OF PATIENTS' MENTAL IMAGES

All health professionals reported <u>no</u> experience of head and neck cancer patients' mental images of the disease, and stated this was not something that patients raised

during conversations with them. The clinic nurses felt that context may be an important in this as during their usual contact with patients there was not the time available to get into deeper conversations with patients where these sorts of things may be expressed.

Despite the lack of direct experience however, there was a fair degree of openness to the notion that HNC patients may visualise their disease. Pam suggested the timing of their contact in the clinic may lack synchronicity with the forthcoming of these kinds of thoughts.

> "I'm dealing with people right at the start where so many of them will be in shock, and then they go for their treatment and I don't see them during this point, and then I see them after the treatment when, hopefully, the cancer's gone, and they're maybe not thinking at that point … …a different time in their journey with the cancer. You know, that may be the time, you know if you were to think of it, that may be the time – I don't know." [Pam, p16]

While Michael – notably the most enthusiastically interested of the HPs – also pointed to the norms and constraints of clinic interactions as probable reasons why patients' mental images were not related to staff – it is simply not something that is discussed.

> "Yeah I mean I think people with cancer have, they're- I think they probably all must have some sort of visual image of what's going on inside them, and I think people sort of often have this thing of something spreading all over the place – you know it's this- and that it's spread elsewhere in your body and um, I… you know I've never delved too deeply into just what their, you know what their imagery is of what's wrong with them. And I think that would vary hugely from patient to patient, but I think the general thing would be of this nasty thing that's

> spreading all over the place you know, that kills you. Is, is probably what I think they… But I've never actually explored that." [Michael, p17]

Intriguingly, the only HP who reported having had any experience of any kind of patients' mental images appeared more sceptical about the possibility that HNC patients may visualise their disease.

> "Very occasionally, em in the past when I've treated breast cancer, I've come across more of that sort of thought… …To be honest with this group of patients – at least in my experience, I'd be fascinated if your, your data shows something different – but they tend to just very much accept what they've got and they want to get on with the treatment. I don't – I can't recollect anybody describing in a visual way their head and neck cancer to be honest." [Cameron, p6]

In part this perception was based on his conception and experience of HNC patients as a more distinct patient group – particularly in terms of deprivation. HNC patients, he felt, were generally very accepting of their condition, practical, and did not appear to do a great deal of 'soul-searching' as a result of their diagnosis – the 'archetypal' HNC and breast cancer patients, for example, would be diametrically opposed.

> "…You know it's the sort of group of patients they are you know, and you know a lot of them their life has been spent around you know going to the pub meeting their mates, having a few pints and talking about the football, you know and just cause suddenly they've got cancer doesn't necessarily mean that they, they're gonna be – suddenly become very introspective overnight you know." [Cameron, p16]

Together with this conception of the typical patient group, the majority lacking interest in seeing scans etc, and the fact that HNC patients can often feel or even see their cancer – whereas bowel or lung patients for example cannot, as per his greater use of imagery with other groups – Cameron felt that this group were less likely to visualise their disease.

5.6.3.5 SUMMARY FINDINGS GROUP 2: HEALTH PROFESSIONALS

These findings demonstrate that head and neck cancer patients, and their partners may be exposed to a range of visual stimuli during their routine interactions with clinicians. The use of real clinical images and images related through visual language varies in terms of the context and purpose of the encounter, and the role of the health professionals – nurses reporting little use of clinical images. However this group may be exposed to both 'real' images of the cancer revealed through scoping examinations and the production of scans; and constructed images such as generic anatomical diagrams and clinician sketches. Health professionals also report some use of visual language involving similes or metaphors as a way of explaining the cancer, while some unconscious conveying of images through the use of visual language was also evident in the transcripts. This small sample of clinicians was largely unaware that patients may visualise their disease, and had little experience of such images. Furthermore there was a prevailing perception that head and neck cancer patients typically would not generate mental images of their disease, founded in the demographic profile of this patient group and health professionals' experiences with them.

5.7 CONCLUSIONS AND IMPLICATIONS

Patients' mental images of their cancer appear to be a largely private phenomenon. Patients and partners report never discussing their images with anyone, and health

professionals exhibited little knowledge of these. Despite the hidden nature of this kind of visual knowledge of the disease mental images seemed to play an important role in how participants understood their cancer and the purpose and outcomes of the treatments they were undertaking. In view of the novelty of mental images as a research topic, and the fact that these images appeared to be significant, yet were concealed, the question arose, has any reference been made to the existence of such images in research already undertaken with HNC patients? This question was a key motivation in the development of the second empirical phase of the thesis – a meta-synthesis of qualitative studies – which is described in the following chapter.

Examination of the perceived origins of patients' images indicated that communication with clinicians may be a prime factor. The clinical encounter may expose patients and anyone attending with them to a variety of visual stimuli, and this appeared to exert a powerful influence over how the cancer was conceived of. The manner in which visual concepts appeared to be used to by patients to represent treatments was reflected in the application of their perceived impact to the patients' original mental images of the cancer (the 'responsiveness' of the image). Given the apparent richness of clinical interactions in shaping participants' interpretations of the disease it may be a concern that HPs themselves are unaware of the power of the material and verbal images they are using.

The findings of this pilot study suggest that some head and neck cancer patients do generate a mental image of their disease, and that this reflects their understanding of what is wrong with them. Individual images varied extensively, though anatomical location, colour, and shape were the most salient properties. Participants in this study were able and willing to talk how they visualised the cancer, and what this meant to them. The images they produced were assessed in terms of accuracy by each individual,

and the fluency and specificity of the manner in which these were described suggests a 'reality' to the reported mental images, as does participants' logical and particular accounts of their origins. The findings presented herein tend to confirm that image re-production in the context of a research interview is both feasible and acceptable to these patients, and an effective way of accessing internal mental images of the cancer. Essentially the efficacy of the implementation process constitutes a 'green light' for replication of this method in the larger study.

5.7.1 SHAPING THE FOCUS OF THE MAIN STUDY

In addition to testing out the proposed method for accessing patients' mental images, the purpose of the pilot study was to inform the design and focus of a larger study. The salient findings were therefore discussed by the research team and three possible options were identified:

1. Focus on the further elucidation of the origins of patients' mental images as relevant to clinical practice.
2. Explore the congruence of patients' and partners' mental images of the cancer and illness perceptions.
3. Examine the role of mental images in patients' understandings of both the cancer and treatments

This section will delineate the rationale and proposed design for each of these options alongside some of the anticipated difficulties of pursuing these.

5.7.1.1 OPTION 1: SOURCING THE ORIGINS OF PATIENTS' MENTAL IMAGES

As anticipated in the design of the pilot study, and in accordance with Harrow et al's (2008) findings, there was evidence of health professionals influencing how patients visualised their cancer in the pilot study. This influence was sometimes mentioned by

patients themselves when pondering why they visualised their cancer a certain way, as well as being interpreted by the researcher. Additionally it appears that patients may be exposed to a range of clinical images during routine appointments, and thus far much of the literature surrounding clinician-patient interaction has focussed on verbal content and the provision of written information (Gamble, 1998; Semple & McGowan, 2002; Rodin et al, 2009). Despite the apparent lack of attention to the use of clinical images however, the communicative value of visual materials has been advocated by several authors (Houts et al, 2006; Posma et al, 2009; Newton, 2010), though the effects of such exposure in terms of patients' understandings of their disease has yet to be determined

One possibility for the larger study was to explore this posited influence further, by investigating patient-doctor communication about the cancer and patients' mental images. This could be achieved by audio recording consultations and then linking the specific dialogue with subsequent patient interviews. Clinician documentation of the material images shown to patients' during consultations would also allow subsequent comparison of these with patients' mental images of the disease. Analysis could then identify any relationships between the interactions – in terms of verbal and material imagery – and patients' beliefs and mental images of the cancer.

The tape recording of consultations for research purposes has been used in a variety of disease contexts including cancer, and has been found to be within the bounds of acceptability for patients (Tattersall, 2002; Themessl-Huber et al, 2008). However in this instance there would be a number of ethical issues, particularly regarding the timing of gaining consent.

It would be desirable to capture the initial diagnostic encounter, as explanation of what the cancer is may be most pertinent at this point. This is obviously problematic however

as eliciting consent immediately prior to the consultation would be shockingly insensitive, and before this point – i.e. on a previous visit on an 'in case it is cancer' basis – also somewhat insensitive and impractical in terms of the time and resources required. The alternative to would be to record consultations as matter of course and seek consent from patients with a confirmed cancer diagnosis afterwards, but again this involves a level of intrusion and retrospective consent is fraught with ethical and practical difficulties.

5.7.1.2 OPTION 2: EXPLORING THE CONGRUENCE OF PATIENTS' AND PARTNERS' MENTAL IMAGES

To our knowledge, no research has yet been published which has explored partners' mental images of patients' disease. The pilot study showed that partners may also formulate mental images which reflect their understanding of the cancer, and given the previously cited importance of the partner's role in providing support to patients (Pitceathly & Maguire, 2003; Rozntowski et al, 2005; Konski et al, 2006), the disparity between couple's mental images of the disease and the implications of this may merit scrutiny. Previous research has demonstrated that incongruence of patient-partner beliefs is linked to poorer outcomes in a range of conditions (for example Kaptein et al, 2007; Dempster et al, 2010). If mental images do represent illness beliefs, externalisation may facilitate discussion of these and the assessment of any discrepancies between patients and partners.

One possibility would be to recruit couples and simply re-enact the data collection process employed during the pilot, perhaps incorporating some objective analysis of the dimensions of patients' mental images and links to specific beliefs. There are several issues with pursuing this option however. Due to the demographic profile of the HNC population – an abundance of unmarried, older men – it may be difficult to recruit

sufficient numbers. Accessing potential participants would probably require both parties were present, and this may compromise the ability of each to consent freely, one feeling a certain pressure to take part if the other party wants to.

Whether interviewed together or separately, couples research is subject to further ethical concerns. Individual confidentiality concerning sensitive issues such as thoughts and feelings about one's or one's partner's cancer may be compromised, due to knowledge of the other's participation and the potential ability to discern their account in publications (Zipp & Toth, 2002; Peters, Jackson, & Rudge, 2008). This may be pertinent given the apparent private nature of mental images. Additional difficulties relate to the influence of the partner's presence in joint interviewing which may influence the accounts by producing greater agreement, or altering the manner in which each party presents themselves (Zipp & Toth, 2002; Boeije, 2004).

5.7.1.3 OPTION 3: INVESTIGATING THE UTILITY OF MENTAL IMAGES AND VISUAL CONCEPTS IN PATIENTS' UNDERSTANDINGS OF THEIR CANCER AND TREATMENT

The evident importance of visual concepts – images embedded in language – in patients' comprehension of treatments such as radiotherapy, suggested that more attention to these was warranted, as they indicated a role for images in understanding beyond that of explicit mental images. Further we discovered that patients' mental images of the cancer were sometimes responsive to new information, for example health professionals' explanations of the impact of surgery on the cancer, and this evolutionary property of mental images raised the possibility of longitudinal investigation.

Therefore a third potential design for the main study was identified – a longitudinal study involving a sample of HNC patients interviewed at two different time points – prior

to commencing treatment and one to two months after treatment completion. The investigation of partners and HPs would be dropped, and this design would enable us to examine patients' beliefs about what was going on inside their bodies, in terms of the cancer's action and the action of the treatment, over time with particular reference to mental images and the development of these. Understandings which, as the pilot findings suggest, may be reflected as much in the use of visual concepts embedded in language, as in mental images.

The novelty of a longitudinal study was also appealing as the overwhelming majority of qualitative research is cross-sectional, and it would counter the obvious criticism of using retrospective accounts when attempting to investigate image evolution. The obvious drawback with undertaking a longitudinal study with this patient group however is the potential loss to follow-up due to death or increasing ill-health. That said, a certain level of attrition is expected in any longitudinal work, and the acquisition of a large enough sample should ensure a decent proportion were able to participate in the second interview.

This third option was therefore selected for perusal in terms of the larger study, and the rationale and details of the design are further outlined in the opening part of Chapter 8.

5.8 CHAPTER SUMMARY

This chapter has presented the design and execution of the first empirical phase of this project, a pilot study with a small sample of head and neck cancer patients, their partners, and relevant health professionals. The findings of this study appeared to establish the feasibility and acceptability of the proposed methods of accessing mental images of the cancer, and informed the direction of the later study (reported in Chapters 8 and 9). Images of the cancer tended to be private, and were not disclosed to others

despite appearing important to patients' overall understandings and experiences of the disease. The hidden nature of patients' mental images provided the stimulus for the development of the second empirical phase of the thesis – a meta-synthesis of existing qualitative research on the experience of head and neck cancer – and the design and findings of this endeavour are presented subsequently, in Chapters 6 and 7.

6 A META-SYNTHESIS OF QUALITATIVE STUDIES OF THE EXPERIENCE OF HEAD AND NECK CANCER – PAPER IDENTIFICATION AND APPRAISAL

6.1 INTRODUCTION

The previous chapter reported the findings of a pilot study which revealed a hitherto hidden, but seemingly important, aspect of HNC patients' experiences – their mental images of the cancer. Together with the reported lack of qualitative research with this patient group, and paucity of literature which has explored patients' visual conceptions of disease, it was decided to investigate whether any allusion to the notion that HNC patients may visualise their disease has been made in existing research. The meta-synthesis then served two functions: enabling the assimilation and scrutiny of relevant papers for references to mental images and visual concepts; and, through integrating and re-interpreting the original findings, yielding an insight into patients' broader experiences of head and neck cancer. This chapter will first provide some background to the relatively new field of synthesising qualitative work, outlining the potential value of such an endeavour, some of the conceptual controversy surrounding the concept, and the development of a proliferation of methodological approaches. It will then describe Noblit & Hare's (1988) five-stage meta-ethnography method, and justify the selection of this procedure as the basis for our own approach to the synthesis, and the rationale behind it. The bulk of this chapter is devoted to delineating the implementation of stages one to three of the process in the form of a 'worked example'. This includes defining the scope of the synthesis, developing and enacting a search strategy and the subsequent selection of papers, and the scrutiny of the characteristics of the included studies. Essentially stages one to three comprise the data collection part of the meta-synthesis

process, the following chapter will then present the implementation of the analytical part of the process – stages four and five – and the findings from this endeavour.

6.2 BACKGROUND

The synthesis of qualitative research involves the collating of similar studies to produce – rather than a review of the aggregated findings – a secondary interpretation of the body of work. Essentially the aim is to give meaning to a set of studies which advances upon the original authors' conceptualisations.

6.2.1 THE VALUE OF META-SYNTHESIS

The nature and value of synthesising qualitative research is succinctly expressed by Finlayson & Dixon (2008, p59), recalling a Buddhist parable (Ireland, 1997) about blind men endeavouring to identify an elephant.

> "On feeling the trunk, one proclaims it to be rather like a snake; while another, on feeling the ear, explains it is more like a fan; yet another, upon touching the legs, describes the beast as tree-like…"

It requires the merging of all the men's accounts to truly depict the elephant. Similarly, merging or synthesising the accounts of individual studies on the same theme enables us to gain the richest possible description of other phenomena, beyond the conceptualisations of the original authors.

Synthesis also counteracts the age-old problem of isolated researchers continually reinventing the wheel (Walsh & Downe, 2005, p205) by neglecting to adequately integrate their findings and theory into the context of previous work (McCormick et al,

2003, p933); and enables the best use to be made of qualitative data, by advancing knowledge and conceptual theory beyond a series of single studies, and thus heightening the accessibility of, and the potential for impact on, real world policy and practice (Finfgeld, 2003, p901).

6.2.2 CONCEPTUAL CONTROVERSY

There is considerable debate around the merits, and indeed the feasibility of, synthesising qualitative studies in this manner. The key criticism of the method is that such a synthesis is conceptually unsafe and lacks credibility, as the findings of qualitative studies are by their nature bound to a specific context, place and time (culture), and to attempt to generalise from these is inappropriately reductionist, and destroys the integrity of the individual studies (Sandelowski et al, 1997, p366).

However those in favour refute the reductionist allegation, claiming that because the aim of synthesising is to generate new insights by interpreting and giving meaning to a set of studies, it is not reductionist at all, but congruent with the nature and principles of qualitative research (Walsh & Downe, 2005, p205). And while individual experiences are unique, there are likely to be some common threads of experience which transcend the contextual boundaries from which they were retrieved.

6.2.3 THE METHODOLOGICAL DIVERGENCE OF QUALITATIVE SYNTHESIS

Despite some opposition to the notion of synthesising qualitative work, interest in it has snowballed over the last two decades, and there have been several methods developed for synthesising qualitative work, which go by different labels. A critical stimulus for the explosion of methodological debate in this area was the publication of Noblit & Hare's (1998) 'meta-ethnography' approach to bringing together the findings of ethnographic studies in an interpretive way.

Meta-ethnography laid the groundwork for the evolution of other approaches toward the same goal, and its influence is perceptible in these (Bondas & Hall, 2007, p115). This seminal work remains a frequently cited baseline method in published meta-syntheses (Thorne, 2004, p1345). Meta-study, meta-ethnography, and grounded formal theory approaches can all be considered branches of meta-synthesis – a term now evolved to encompass the range of approaches (Thorne, 2004, p1343) – in that their intended product is an interpretive synthesis; while meta-summaries or qualitative systematic reviews involve the aggregation of qualitative evidence.

Meta-study is perhaps the most comprehensive approach incorporating analysis of the original studies' theory (meta-theory), methods (meta-method), and findings (meta-data analysis). Meta-ethnography was initially designed to synthesise the findings of several ethnographies (Noblit & Hare, 1988), and since has been applied to qualitative research across the methodological spectrum. Finally grounded formal theory is specific to the traditions of grounded theory, involving synthesising the findings of several grounded theory studies to produce a 'grounded formal theory'. Bondas & Hall (2007, p115) cite Paterson et al (2001), and Kearney (2001), as the key cultivators of meta-study and grounded formal theory, respectively.

It would be remiss to regard these styles as distinct and accepted entities however -the credibility, truthfulness, and value of each approach, and the technical or procedural steps advocated, are hotly contested.

In light of the variety of – sometimes diametrically opposed - philosophical and methodological bases upon which qualitative work is grounded, some researchers argue against the inclusion of studies employing different perspectives in the belief that the inherent differences in the kinds of 'knowledge' produced (the significance of such

differences is itself a matter of debate), render the findings incompatible for translation (McCormick et al, 2003, p935). The contrary view is that in fact the incorporation of studies from multiple perspectives is congruent with the concept of 'triangulation' – a reputed credibility-enhancing technique involving the analysis of data generated from more than one theoretical/methodological perspective in an effort to negate the limitations of singular methods – and therefore synthesising the concepts across a range of methodologically varied studies would also reaffirm the integrity of the interpretation (Finfgeld, 2003, p902).

The decision to exclude papers based on a critique of the scientific quality of the study is too an area of conflict, much of which emits from a general controversy over how to appraise qualitative research. This issue is discussed in more depth in 'stage 4' of the methods section of this chapter.

Another key difference between approaches is in what parts of the papers constitute the 'data' to be interpreted. The meta-study method advocates in-depth three-pronged analysis of the theory, methods and findings of the studies; while meta-ethnography designates the findings – the original authors' interpretations, not the raw data therein (Noblit & Hare, 1988, p32) – as the focus of synthesis (Bondas & Hall, 2007). In the latter instance however, this should not preclude due consideration of methodological differences – that context from which the findings were retrieved.

In the current situation of a proliferation of disparate approaches, and a lack of consensus over formulaic and technical issues, it was deemed appropriate to reference Noblit & Hare's meta-ethnography method as the primary basis for our approach, and the reasons for this selection are elucidated in the overview of which follows.

6.2.4 OVERVIEW OF NOBLIT & HARE'S APPROACH

Once the area of interest has been determined, there are essentially five broad stages to the synthesis process:

1. Defining the Scope: The boundaries of the investigation must be drawn up in terms of the topic selection, the search strategies to be used, the databases to be searched, and, where appropriate, a time period.
2. Creating the Data-Bank: The search strategy is carried out, and the relevant papers identified and assessed individually on quality to create the bank of data.
3. Scrutinising the Studies: The papers must then be carefully scrutinised and classified according to the context, concepts and main theory or explanation.
4. Translating concepts & relating the studies: The concepts should be compared or translated across the studies to determine what reciprocal or contrasting relationships exist between the papers.
5. Synthesising translations: Once all the evidence has been pooled in this way, the translations should be synthesised to produce a secondary interpretation of the original findings.

The final 'product' of a meta-ethnography is a secondary interpretation of the collective authors' original interpretations – not a re-analysis of the raw data. The aim is to conceptualise beyond the original authors, and thus to gain a deeper insight into the topic.

We chose this mode of synthesis as the basic formula for our own, as it was emphasised as one way to carry out a synthesis (Noblit & Hare, 1988, p25), encouraging elaboration and innovation, and therefore was less prescriptive, including scope for researchers to use their own initiative in putting these stages into practice. It is also a

well-practised and established methodology, and as this was the first endeavour of this kind within the research group, it was felt to be a reasonable choice.

6.3 RATIONALE FOR THE META-SYNTHESIS

The rationale behind the meta-synthesis was based on the initial findings of the two earlier phases of this project - the qualitative pilot study (reported in Chapter 5), and the process of reviewing the literature.

The findings of the pilot study demonstrated that for those who had a mental image, their experience of HNC was inextricably linked to these images, and yet this facet of experience has been largely neglected. It was a private phenomenon, and partners and health professionals were essentially unaware that a) some patients visualised their disease, and b) that these images appeared important in terms of their understanding of the cancer, and therefore how it was experienced. Patients' understandings of treatments also appeared to relate to images in the form of visual concepts embedded in language, and this too was generally undisclosed. Much of the existing research with HNC patients is quantitative in nature, and while illness beliefs have been studied in relation to quality of life, the questionnaire assessment of these beliefs does not consider the form they may take, and does not elucidate the role of visual knowledge (in the form of mental images and other visual concepts) in patients' understanding. If the phenomenon of mental images has been revealed elsewhere then, the most likely source was qualitative studies. An apparent lack of qualitative research into HNC patients' experiences is oft-cited in the literature (Wells, 1998, p841; McCabe et al, 2008, p61). The head and neck specific quality-of-life literature is vast due to the radical treatments and functional impairments this patient group face, but it is arguable how adequately quantitative measures can represent patients' experiences, and so this is a potentially important deficit.

Qualitative methods are ideally suited to breach the gap in the knowledge as their strength is to illuminate subjective perceptions, and can research of this kind can best capture the depth and richness of patients' experiences of serious illness. However these are typically small-sample inquiries and are often criticised for the lack of 'generalisability' to the broader patient population, in the quantitative sense of the word (Sandelowski et al, 1997, p367). Like much qualitative work, they are also widely dispersed across the literature, and difficult to assimilate. Given the apparently covert nature of imagery, and in the climate of a reputed dearth of qualitative evidence, two questions emerged:

1. What is reported about the experience of head and neck cancer?
2. In what way do mental images or other visual concepts feature in existing accounts of patients' experiences?

The meta-synthesis aims to answer these questions by locating and synthesising the findings of the relevant qualitative literature.

6.4 METHODS

The remainder of this chapter will delineate the methodological approach to the synthesis, grounded in Noblit & Hare's (1988) procedure, through stages one to three. These stages comprise what is essentially the design and data collection process:

1. Defining the scope of the synthesis
2. Creating the Data-Bank (Implementing the search strategy)
3. Scrutinising and classifying the papers

As iterated at the start of this chapter, the final two stages of the process, which are analytical in nature, together with the findings of the meta-synthesis, are outlined in the subsequent chapter.

6.4.1 STAGE ONE: DEFINING THE SCOPE

The first stage of the synthesis is to define the scope of the investigation in three respects. The particular topic under study must be determined in terms of the population of interest, the topic of interest, and the types of 'evidence' desired – in this case qualitative research studies. Boundaries must then be established in terms of the locations in which to search for relevant papers (i.e. particular databases), and finally a search strategy must be devised to accomplish retrieval. This section will report on how the scope of this meta-synthesis was defined in each of these respects.

6.4.1.1 SCOPE

The scope of the topic was deliberately broad, as the aim was to recover all potentially relevant research. Target papers fulfilled 3 criteria:

1. Qualitative studies
2. Subjects – HNC patients, or any subgroup of
3. Topic – Experience of the disease as a whole, or any sub-part thereof

No time restrictions were applied as it was anticipated that the number of relevant studies would be minimal. Each database was searched from conception to the present day.

6.4.1.2 DATABASES

Seven databases were selected to search – Medline, Embase, Cinahl, British Nursing Index & Archive, ASSIA, Social Science Citation Index, and PsycInfo. The selection was based on the content and scope of each database, and the likelihood that pertinent articles would be contained therein. The remit and coverage of these databases is illustrated in table 10.

Table 10 - Overview of the databases

DATABASE	SCOPE	SCALE	COVERAGE
MEDLINE	Medicine, Nursing, Dentistry, Veterinary medicine, Allied health, and Pre-clinical sciences. [The United States National Library of Medicine's premier bibliographic database]	The largest biomedical database available. International coverage – approx. 4,600 current biomedical journals published in the U.S. and 70 other countries. Over 13 million citations.	1950 – present
EMBASE	Biomedicine, Pharmaceutics, Psychiatry, and selected coverage of Nursing, Dentistry, Veterinary medicine, Psychology, and Alternative Medicine. [Elsevier].	Over 3,500 international journals. (Like Medline but with more European journals)	1980 - present
CINAHL (Cumulative Index to Nursing and Allied Health Literature)	Nursing and the Allied Health professions	Includes citations from over 2,500 journals which are currently indexed.	1982 – present
BNI & ARCHIVE (British Nursing Index & Archive)	Nursing, Midwifery and Community Healthcare (English language only – mainly UK).		1985 – present

ASSIA (Applied Social Sciences Index and Abstracts)	Health and the Social Sciences (Psychology, Sociology, and Politics among other subject areas).	Over 375,000 articles from 500 journals from 16 countries inc the UK and the U.S.	1987 - present
SSCI (Social Science Citation Index)	A multidisciplinary index of the Social Sciences.	More than 1,725 journals across 50 social sciences disciplines, and selected relevant items from over 3,300 international scientific and technical journals.	1970 – present
PSYCINFO	Psychological, Social, Behavioural, and Health Sciences. [American Psychological Association]	-	1806 – present

6.4.1.3 SEARCH STRATEGY

6.4.1.3.1 LOCATING QUALITATIVE RESEARCH

Locating qualitative studies is notoriously difficult. The difficulties mainly stem from the wide dispersal of publications, and database/indexing inadequacies. Qualitative research may transcend traditional boundaries topic-wise, and cross disciplines, and is therefore published in a broad range of journals, including those which are primarily biomedical publications (Barbour & Barbour, 2003). A proportion of qualitative research is published exclusively in books, and can be overlooked by electronic searches (Britten et al, 2002).

An array of databases may hold qualitative studies within them, and this is too problematic. Some may preclude some of the more prominent qualitative journals, and where search strategies for finding qualitative research have been developed often there has been a blind eye turned to the issue of comprehensiveness of database coverage (Barbour & Barbour, 2003).

Indexing systems/practices may differ significantly across databases. This inconsistency means a thorough search requires using multiple databases and search filters appropriate to each database (Wong et al, 2004). Database and indexing systems are also not so well developed as they are for quantitative work (Shaw et al, 2004) - for example a number do not yet hold 'qualitative' as a subject heading.

The word qualitative can be used in several contexts, and have various meanings. It is often used erroneously to describe studies which are actually quantitative in design, and the incorrect/questionable labelling of studies as qualitative – design, methods and/or analysis falsely claiming to be such – can further compound the difficulty of searching (Grant, 2004).

The titles assigned to qualitative studies are often what might be termed 'creative' or 'colourful', and tend to refer more to the findings than the methodology, which can lead to wrongful indexing, and can make it considerably hard to determine initial relevance from the title alone (Wong et al, 2004), and to root them out on this basis.

And finally, perhaps because synthesising qualitative work is relatively new, there's also a lack of established optimised search strategies (OSS) available for searching the literature.

6.4.1.3.2 THE SELECTED STRATEGY

With these difficulties in mind, it was decided to replicate an existing strategy involving the concurrent use of three search strings for retrieving qualitative work – based on thesaurus terms, free-text terms, and broad-based terms. These were developed initially by Shaw and colleagues (2004) in a comparison of usefulness, and later replicated by Flemming & Briggs (2007).

The 'thesaurus terms' string is built on databases' indexing systems, and refers to the keywords used to index the records in an electronic database (also known as 'subject headings'). The way in which qualitative work is indexed varies according to different databases, so this strategy was tailored to suit each database – and the scope of this strategy was the indexing system.

The 'free-text terms' string comprises nearly fifty terms referring to different qualitative methodologies and are therefore likely to identify qualitative studies. The list was developed by Shaw and colleagues through reflection on their expertise and existing methodological filters, and the scope of this strategy was the title, abstract, and key

words of papers. Finally, the 'broad-based terms' string was the simplest of the 3, comprising only three simple descriptors – qualitative, findings, and interviews.

Shaw found that while each of these strategies retrieved relevant papers, they all also missed relevant papers. Therefore they recommended using more than one strategy in combination in order to maximise recall (Shaw et al, 2004; Flemming & Briggs, 2007). Therefore as the aim was to recover all relevant published papers, this strategy was appropriately highly sensitive.

The original Shaw strings were modified slightly by replacing those terms which referred to their search topic – breast-feeding – with appropriate HNC-relevant terms for each database (see Appendix 14 for full details of the search strategy used in each database). The head and neck cancer terms used were consistent across all three strings, but varied across the databases according to the specific thesaurus terms/subject headings for the topic - citing and exploding these was considered the most reliable way of accessing papers referring to the target subjects. The exception was PsycInfo which lacked an indexing term for HNC, and so the search was made by keywords (see table 11)

In total, twenty-one separate searches were carried out across the seven databases.

Table 11 - HNC terms adopted according to database

	Medline	Embase	Cinahl	BNI & Archive	ASSIA	SSCI	PsycInfo
'Head and neck cancer' [Subject/thesaurus/topic term]	✓	✓	✓	✓	✓	✓	……
'Head and neck neoplasms' [Subject/thesaurus/topic term]	✓	✓	✓	……	……	✓	……
'Head and neck tumor' [Subject/thesaurus/topic term]	……	✓	✓	……	……	……	……
'Head and neck cancer' [Keyword search]	……	……	……	……	……	……	✓

6.4.2 STAGE TWO: CREATING THE DATA-BANK

The second stage of the synthesis process is to implement the search strategy and identify relevant papers – in other words to create the bank of data which will be subject to the synthesis. This section will recount this process. Beginning with presentation of the output of the search strategy, the process of screening the retrieved papers will then be described. The screening process consisted of four stages. Initially only titles were reviewed, and where sufficient information was given to determine relevance these where retained or excluded. Following this abstracts were reviewed and 109 papers retained for screening of the full texts which was carried out by the research team – each paper subject to two independent reviews. Forty-eight papers were deemed of sufficient relevance and underwent critical appraisal, again by two independent reviewers, and fifteen papers survived appraisal to be included in the synthesis.

The particulars of the screening process will be described in this section. Reasons for the exclusion of papers at the full-text review stage will be explicated. The critical appraisal of qualitative research is in itself a contentious issue, and the arguments for and against quality assessment in the context of a meta-synthesis will be outlined. Finally the decision to appraise the papers will be justified, and the results of the appraisal cited.

6.4.2.1 SEARCH STRATEGY RETRIEVAL RESULTS

Table 12 - Search strategy retrieval per database

	Medline	**Embase**	**Cinahl**	**BNI & Archive**	**ASSIA**	**SSCI**	**PsycInfo**
Records Retrieved	1271	1192	439	*5*	9	68	20
Thesaurus Terms	1271	1192	439	*5*	9	68	20
Free-text Terms	84355 [64567]*	44844 [34865]	3322 [3291]	35	3	14	84
Broad-based terms	72	*7773*	*505*	*5*	15	56	22
Total Records Retrieved	114,311 (figure does not account for duplicates therein)						

[NB: * figures in brackets indicate 'English' and 'humans' limits applied]

6.4.2.2 IDENTIFYING RELEVANT PAPERS: THE SCREENING PROCESS

Upon execution of each search string, the retrieved records were exported to Refworks online reference manager software, which facilitated simple storage and organisation of the records into named folders, from where the screening process could commence. The screening process comprised four stages:

- Stage 1 - Screening of all 114,311* titles → Exclude: 112,885* → Retain: 1,426*
- Stage 2 - Screening of abstracts → Exclude: 1,018* → Retain: 109
- Stage 3 - Screening of full texts → Exclude: 61 → Retain: 48
- Stage 4 - Critical Appraisal → Exclude: 33 → 15 papers included in the synthesis

  (* = figure does not account for duplicates)

6.4.2.2.1 STAGE 1 – SCREENING OF TITLES

Initially all 114,311 records were screened initially for relevance by title by the researcher. Due to the high sensitivity strategy employed, a vast number of patently irrelevant records were retrieved, and the majority could be easily identified and excluded by title alone.

Technical methods of screening the results – such as the application of numerous 'limits' to narrow down electronically retrieved results – were avoided to ensure no relevant record was excluded accidentally. One concession to index-based screening was the application of 'English' and 'humans' limits to three of the largest sets of results – the free-text searches in Medline, Embase, and Cinahl – due to time constraints and

satisfaction that these limits in particular would only exclude irrelevant studies – those involving animals and those published in foreign languages.

In some instances the title of the article was insufficient to make a definitive decision on potential relevance, and it was necessary to consult the abstract of the paper. Where this still proved ambiguous the record was retained until the following stage.

6.4.2.2.2 STAGE 2 – SCREENING OF ABSTRACTS

Secondary exclusions from the graduating pool of 1,426 papers were made by the researcher on the basis of reviewing the abstracts for relevance according to the same broad inclusion criteria – qualitative methods; HNC patients, or any subgroup of, as the subjects; and the experience of the disease, or any aspect of, as the topic.

1,018 records were excluded at this stage, and the remaining 408 records de-duplicated to facilitate acquisition of the full texts. De-duplication indicated 109 distinct potentially-relevant articles retrieved across the twenty-one searches to be reviewed at the next stage.

6.4.2.2.3 STAGE 3 – SCREENING OF FULL TEXTS

The research team reviewed the full texts of the 109 remaining records. Each paper was assessed for relevance by two researchers independently, and ambiguous cases were reviewed by the whole in order to make definitive inclusions/exclusions.

Table 13 **- Primary reason for exclusion of papers at stage 3**

Justification for Exclusion	**Details**	**No. Papers**
Not Qualitative	Quantitative	26
	Literature-based	13
Insufficient Focus on Target Topic	……	7
Insufficient Focus on Target Subjects	……	7
	Thyroid Cancer	2
Non-English Language	……	6
Total		61

The most prevalent reason for exclusion was that the paper did not employ qualitative methodology – a total of 39 papers were excluded on this basis. But the fact that this was not readily apparent or was inconclusive in the abstracts reviewed at the preceding stage reflects the difficulties in locating qualitative research.

The decision was taken at this stage to exclude papers which referred exclusively to a sub-set of head and neck cancer patients – those with thyroid cancer - and the rationale for this is as follows. Thyroid cancer is relatively rare, affecting approximately 3 people in every 100,000 in Scotland, with a higher incidence amongst females than males (Cancer Research UK, 2007a). While the thyroid gland is located in the neck, its status as a rare cancer, and its lack of similarity to the other head and neck cancers, means it is often excluded from the group of cancers considered to compose 'head and neck cancer' (Butterworth, 2007), for example it is absent from the National Cancer Institute's definition (National Cancer Institute, 2006).

Thyroid cancer patients go through a different referral path, and are usually managed and operated on through a different hospital department (although occasionally the endocrine surgeon is based in ENT). So the treatment trajectory for thyroid cancer is very

different to that of head and neck cancer, and therefore the overall illness experience is likely to differ significantly too.

This is reflected in the distinction between head and neck cancers and thyroid cancer in the 'International Classification of Diseases Manual' (ICD). Currently in its 10th revision (ICD-10), this manual is a systematic inventory of diseases and other health issues which facilitates epidemiological analysis of inter-country incidences and mortality (World Health Organisation, 2008). The various sites of head and neck cancers are coded between C00-C14 and C30-C32, e.g. laryngeal cancer C32 (ISD Scotland, 2007a). Thyroid cancer (C73) however is grouped with other malignancies of the endocrine system – cancers of the adrenal gland (C74), and 'other endocrine glands and related structures' (C75) (ISD Scotland, 2007b).

The aetiology of thyroid cancer differs markedly from HNC – the former more common in females, with primary risk factors exposure to radiation (especially in childhood), and genetic or biological factors; (Cancer Research UK, 2007b) as opposed to a higher male incidence in HNC, and smoking and alcohol as primary risk factors. There is also little impact of deprivation on incidence in thyroid cancer, which also carries different survival rates. Hence the two patient populations are rather different.

In summary, although thyroid cancer is included in the definition of head and neck cancer adopted for this thesis, given the distinctiveness of this cancer's trajectory and treatment, it was thought appropriate to exclude it from this review which focuses on experiential aspects and seeks to merge the findings of several studies on this topic.

There were 6 potentially relevant foreign language papers retrieved, and it was decided to exclude these also - prior to the application of an 'English' limit on the final 3 searches screened (indicated in table 13).

Partly this was based on a lack of funding/resources for translation of these articles from five foreign languages – French (2), German, Japanese, Dutch and Portuguese. Resource limitations have been cited by others as justification for excluding non-English language papers when synthesising qualitative research (Briggs & Flemming, 2007, p325; Munro et al 2007, p1232).

Coupled with this was concern about the integrity of the translation – attempting to translate 'meaning' into English. As Briggs & Flemming (2007, p325) noted after carrying out their meta-synthesis:

> "Only one study was carried out where English was not the native language, and we experienced some problems that may be because of translation. The themes ascribed to certain phrases by the original authors did not 'translate' across to other papers which described similar themes. Therefore, whilst there were many emergent themes that allow international comparisons, we cannot assume that meaning is transferable across languages and cultures."

While we did not exclude studies from other countries written in English, this report underscored the concerns about the reliability of translation, and cemented the decision to exclude those published in foreign languages. After applying the language and non-thyroid cancer conditions, 48 qualitative papers were considered sufficiently focussed on head and neck cancer patients – the target subjects – and their experience of the disease – the target topic – to graduate to the stage four – critical appraisal.

6.4.2.2.4 STAGE 4 – CRITICAL APPRAISAL

The final stage of the screening process was critical evaluation of the papers. The appraisal of qualitative research is a contentious issue however, and there is considerable debate around its feasibility and appropriate methods for doing so. The main issue with quality appraisal is the lack of consensus as to what constitutes 'good' research (Mays & Pope, 2000). The focus in qualitative studies is on interpreting meanings, not discovering an objective 'truth', and how do you assess an interpretation?

Another difficulty in deciding to critically appraise is determining what form such an evaluation should take. Quantitative rules do not apply, yet any fair and rigorous assessment demands some kind of standardisation. In view of this, there have been numerous checklists or guidelines developed for appraisal, for example - the 'Framework for Assessing Qualitative Evaluations', constructed by the Government Chief Social Researcher's Office (Spencer et al, 2003), and the Joanna Briggs Institute's 'Qualitative Appraisal and Review Instrument' appraisal checklist (JBI-QARI) (Joanna Briggs Institute, 2003).

However, due to the diverse methodologies and theoretical perspectives employed in qualitative work, these are often unsuitable – and there is a lack of consensus between checklist authors on which aspects of research design are most important/better indicators of quality, and little consideration of to what degree flaws in design compromise the integrity of the work (Dixon-Woods et al, 2004).

In this climate, many argue that inclusiveness is more important, and that all patient testimony should be included regardless of the quality of the study, and there are a number of published meta-syntheses which have not included any kind of quality assessment (O'Neill et al 2007; Briggs & Flemming, 2007). Sandelowski et al (1997)

positively argue against exclusion based on quality criteria because of the issues surrounding what constitutes 'good quality' and the questionable appropriateness of using any kind of checklist-type quality criteria, and advise that if quality-based exclusions are made, the criteria informing them must be made explicit.

The alternative view is that given the recent emergence of qualitative synthesis as a method, and the desire to have it taken seriously in the research world, not to appraise would be to compromise the integrity and credibility of the synthesis (Campbell et al, 2003). As long as the quality criteria are made explicit, appraisal can be a valuable part of the selection process, as including poorly designed and executed studies would weaken the basis upon which the secondary interpretation is formulated. Therefore it was decided to evaluate all 47 papers.

6.4.2.2.4.1 Checklists – Friend or Foe?

Two key criticisms of the use of checklist-type assessments are that they are inadequate or inappropriate due to the nature of qualitative research, and that they threaten the truthfulness of qualitative work by providing boxes which some may feel compelled to tick to be accepted as credible (Barbour, 2001). Nonetheless, there are a number of tools which have been developed to aid the process of appraising papers, and when used wisely can be valuable – for example the CASP tool (Campbell et al 2003, Pound et al 2005).

However, the use of appraisal checklists like the CASP has been flagged up as risky. Over-zealous or rigid application of checklists can reduce the value of studies to simply how many procedures deemed to strengthen rigour have been employed. Also, while procedures such as purposive sampling and respondent validation can be valuable, they are not always appropriate or practical, and the absence of these or similar measures

should not necessarily equal a poor paper (Barbour, 2001). Checklists should in fact be used as a pointer or guide to consider key issues, but the reviewer should strive to consider the design, rationale and quality of the study as a whole.

In a comparison of 'unprompted' expert judgement and the use of the CASP tool and another checklist to appraise qualitative papers, it was found that agreement between or within reviewers was no better when using the structured tools, but that they did facilitate explicitness of the reasons for individual judgements (Dixon-Woods et al, 2007).

This transparency in terms of the reasons for including or excluding certain papers, and the varying levels of experience in qualitative methods within the research team – from complete novice to expert – were the main reasons for choosing to use a structured tool.

6.4.2.2.4.2 The Process of Appraisal

After consideration of a few of the more prominent checklists available, such as the Joanna Briggs Institute's 'Qualitative Appraisal and Review Instrument' and the 'Framework for Assessing Qualitative Evaluations', the CASP Qualitative Appraisal Tool was selected. Factors in this choice included its wide previous use in meta-syntheses, clear structure, and length (given that it must be applied to nearly fifty papers).

The CASP tool consists of 3 screening questions and a checklist of 7 further areas for appraisal, with several points to consider in each. We modified the CASP slightly, adding tickboxes marked 'good', 'poor', or 'fatal' to each section, to enable the individual to state clearly whether they felt the flaws therein were minor or serious. There were two 'fatal' flaws identified during the modification of the CASP tool – a) no data presented, and b) no information on how the analysis was carried out.

To the front page, tickboxes for an overall verdict – include, exclude, or discuss – were added, so that each reviewer could make explicit their judgement. The papers were divided randomly into two lots. Each paper was then appraised independently by 2 reviewers, and where there was divergence in recommendations the paper was discussed by all 4 members of the research team to reach a consensus. Fifteen papers qualified for inclusion in the synthesis. The primary reason for exclusion on the basis of CASP appraisal is indicated in table 12. The full results of the evaluation process – each reviewer's verdict and the consensus decision – are provided in Appendix 15.

Table 14 **- Primary reason for exclusion following CASP appraisal**

Flaw	**No. papers**
Primarily Quantitative Methodology	4
Not a Research Article	2
Literature-based Article	1
Personal Account	5
No data presented	4
Lack of data presented	1
No information on data analysis	6
Poor data analysis	1
Mixed sample - lack of focus on HNC patients	1
Topical focus is on HNC services rather than patients	5
Focus on methodology rather than subjects/topic	1
Focus on a concept rather than Subjects/topic	1
Non-quality based: Duplication of existing included paper	1
Total	33

[Note: Table 14 indicates the primary, but not necessarily sole, reason for exclusion of papers.]

Of the 33 excluded papers, in total 9 had no information on the process/method of data analysis cited as a flaw, 6 were criticised due to no original data being presented, and 5 more for a lack of data presented. Specific minor weaknesses are not reported here. One paper was excluded at this stage on a non-quality based issue - it transpired during the appraisal process that it was in fact a carbon-copy of another included study, published under a different title.

The appraisal process indicated that while there is lack of qualitative studies pertinent to head and neck cancer, the quality of the published work which does exist is often questionable – only 15 of the retrieved papers were deemed to be of adequate quality to include.

6.4.2.2.4.3 Challenges in the Appraisal Process

Despite using a standardised tool, as anticipated there was a great deal of subjectivity in its application or interpretation in terms of what was considered to be of an adequate standard where flaws were present, and extensive discussion was required on an individual paper basis.

Those with more qualitative experience were able to make critical judgements relatively simply, but there was a reasonable degree of agreement between the reviewers, and the use of the CASP tool facilitated the transparency of decision-making desired.

The rigidity of application of the two flaws considered fatal, and therefore necessitating exclusion, was also an issue. In respect of those papers which had failed to present any original data whatsoever, this flaw was uniformly regarded as fatal. The other fatal flaw however – no information provided on the method or process of data analysis –

was the number one reason for exclusion of papers, though one exception to this rule was made upon discussion of the individual paper.

The paper by Moore (2004) failed the appraisal in this respect, but it was deemed that there was sufficient data and context provided to make a subjective decision to include it– the themes were judged to have clearly arisen from the data, and in other areas of quality evaluation the paper had excelled. This case exemplifies the need for a degree of expertise in qualitative research, and reasoned flexibility, in order tackle evaluation in a common-sense way.

The thorniest aspect of choosing to appraise was the dilemma of excluding data-rich papers. A number of papers had to be excluded on grounds of quality, despite presenting good original data, and their findings 'fitting' with other sources. It was rather painful to exclude these.

The appraisal process reinforced the difficulties cited previously about the complexity and muddiness of evaluating qualitative work. It also underpinned the need for qualitative researchers to provide original evidence in their explication of findings (something which has been hampered at times by journals' word limits) and to make clear the methods and process of data analysis.

6.4.3 STAGE THREE: SCRUTINISING AND CLASSIFYING THE PAPERS

The next stage of the process was careful reading and classification of the studies in terms of their design characteristics, context, concepts or themes identified in the findings, and conclusion/main argument or explanation.

6.4.3.1 CHARACTERISTICS & METHODS OF THE STUDIES

Semi-structured interviewing was the data collection method of choice in 13 of the studies. Unstructured diaries were used in conjunction with interviews by Wells (1998), and Rodriguez & VanCott (2005) incorporated a focus group into their data collection.

Furness (2006) held focus groups only, though they offered one-to-one interviews where it was preferred by participants as their sample included people living with facial disfigurement who may have found a group setting uncomfortable. Crossley (2003) did not employ traditional qualitative data collection methods, as they were conducting a single case study based on retrospective analysis of serialised diary entries already in the public domain – published in the book 'Snake Oil and Other Preoccupations' (Diamond, 2001).

Two-thirds of the samples were of 'mixed' HNC patients – whose cancers were located at a variety of sites. Three comprised oral cancer patients only, one potential oral cancer patients (10% diagnosed with a cancerous condition), and one was exclusively nasopharyngeal. Patient sample sizes ranged from a case study of 1 to 57.

Two of the studies included another patient group in their sample – lung cancer (Gamble, 1998) and non-HNC facial surgery (Furness, 2006). One included participating patients' caregivers (Mah & Johnston, 1993), and other relevant health professionals (Rodriguez & VanCott, 2005).

Table 15 - Characteristics and Methods of the Included Studies

	First Author	Year	Title	Journal	Sample	Data Collection	Setting/ Country	Data Analysis
1	Chou	2007	An exploration of life attitudes in patients with nasopharyngeal carcinoma	Cancer Nursing 30(4): 317-323	10 naso-pharyngeal cancer patients	Semi-structured interviews	A Taipei Cancer Centre. Taiwan.	Colaizzi's (1978) phenomenological Method
2	Crossley	2003	'Let me explain': narrative emplotment and one patient's experience of oral cancer	Social Science & Medicine 56(3): 439-448	1 oral cancer patient	Retrospective diary analysis	England.	Utilises the concept of 'therapeutic emplotment' (Del Vecchio Good et al, 1994)
3	Fritz	2001	Life experiences of head and neck cancer survivors: A pilot study.	ORL Head and Neck Nursing 19(4): 9-13	3 mixed HNC patients	Semi-structured interviews	A Comprehensive Cancer Centre. USA.	Colaizzi's phenomenological method (Streubert & Carpenter's 1995 adaptation)

4	Furness	2006	Coming to terms: a grounded theory of adaptation to facial surgery in adulthood	Journal of Health Psychology 11(3): 453-466	29 facial surgery patients: 19 mixed HNC, 2 skin cancer, 8 non-cancerous conditions	Focus groups, (Individual interviews where preferred)	Hospitals in the area. England.	Grounded Theory
5	Gamble	1998	Communication and information: the experience of radiotherapy patients	European Journal of Cancer Care 7(3): 153-161	15 radiotherapy patients: 9 mixed HNC and 6 lung cancer patients	Semi-structured interviews	A Hospital. England.	Grounded Theory
6	Larsson	2007	Needing a hand to hold: Lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy.	Cancer Nursing 30(4): 324-334	9 mixed HNC patients	Semi-structured interviews	University Hospital Oncology Clinic. Sweden.	Colaizzi's phenomenological Method
7	Larsson	2003	Lived experiences of eating problems for patients with head and neck cancer during radiotherapy	Journal of Clinical Nursing 12(4): 562-570	8 mixed HNC patients	Semi-structured interviews	2 Oncology Clinics. Sweden.	Colaizzi's phenomenological method

8	Llewellyn	2005	Striking the right balance: a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer	Psychology, Health & Medicine 10(2): 180-193	15 mixed HNC patients	Semi-structured interviews	HNC Clinics at 2 Hospitals. England.	Framework Analysis (Ritchie & Spencer, 1994)
9	Mah	1993	Concerns of families in which one member has head and neck cancer	Cancer Nursing 16(5): 382-387	4 mixed HNC patients, plus 4 caregivers	Brief semi-structured open interviews throughout the treatment trajectory	Metropolitan Teaching Hospital Surgical Oncology Unit. Canada.	Constant Comparative Approach (Grounded Theory)
10	Moore	2004	Communicating suffering in primary stage head and neck cancer	European Journal of Cancer Care 13(1): 53-64	18 mixed HNC patients	Semi-structured interviews	A Texas Cancer Centre. USA.	No information (states only that the interviews were 'transcribed and then coded')

11	Rodriguez	2005	Speech impairment in the postoperative head and neck cancer patient: nurses' and patients' perceptions	Qualitative Health Research 15(7): 897-911	9 mixed HNC patients, plus 6 nurses	Written semi-structured interviews (patients), Semi-structured interviews + one focus group (nurses)	Tertiary Care Institution. USA.	Content Analysis
12	Roing	2007	The uncanny mouth – A phenomenological approach to oral cancer.	Patient Education & Counseling 67: 301-306	7 oral cancer patients	Semi-structured interviews	University Hospital Oral & Maxillofacial Surgery/ Hospital Dentistry Clinic. Sweden.	Guided Existential Reflection (van Manen, 1990)
13	Scott	2006	Patient delay in oral cancer: a qualitative study of patients' experiences	Psycho-oncology 15(6): 474-485	17 oral cancer patients	Semi-structured interviews	Hospital HNC Service. England.	Framework Analysis (Ritchie & Spencer, 1994)

14	Scott	2007	The process of symptom appraisal: cognitive and emotional responses to detecting potentially malignant oral symptoms	Journal of Psychosomatic Research 62(6): 621-630	57 symptomatic potential oral cancer patients – 90% benign, 10% cancer	Semi-structured telephone interviews (this was a mixed-methods study, but only the interview findings are presented)	Teaching Hospital Oral Medicine Dept/ HNC Service. England.	Framework Analysis
15	Wells	1998	The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment	Journal of Advanced Nursing 28(4): 840-848	12 mixed HNC patients	Unstructured diaries and semi-structured interviews	Hospital Radiotherapy Dept. England.	Not tied to one specific approach – qualitative analysis, full description p843

6.4.3.2 STUDIES' MAIN FINDINGS AND CONCLUSIONS

The second aspect of stage three was to scrutinise and elucidate the fifteen papers' findings or themes, and their conclusions. During this process the studies' themes and the raw data therein was also examined for any references to the phenomenon of mental images or evidence of figurative images, and the findings in this respect are presented in the penultimate section of this chapter. As shown in table 14 below, the papers' findings pertained to several facets of the experience of head and neck cancer. Two papers' themes pertained exclusively to the impact of the experience of HNC on the individual's outlook on life (no.1) and view of themselves (no.10). The majority of papers described elements of the nature of the experience of cancer and treatments (no's 2, 3, 4, 6, 7, 9, 12, and 15). One paper's findings related the experiences of post-operative patients for whom communication is compromised (no.11); two presented mostly categorical themes on the information needs of patients (no.5) and their expectations (no.8). The final two papers pertained to the pre-diagnosis period and the process of symptom appraisal and help-seeking (no's 13 and 14). Classification of the primary focus of each of the studies is outlined in the subsequent section.

The majority of papers presented their findings in the form of qualitative themes, though the clarity of these varied extensively – from simple categories of findings to expressive, meaningful theme labels. The 'cloudiness' of some of the thematic labels, and the implications of this on the translation of the findings, is outlined in the subsequent chapter. Two papers presented findings in the form of theoretical models derived from their data – no.2 a model of adaptation to oral cancer, and no.4 a model of adaptation to facial surgery. Paper no.2 was an application of the concept of 'therapeutic emplotment' to oral cancer, and this is evident in the thematic labels. Similarly, paper no.14 was an application of Leventhal's theory of the cognitive and emotional appraisal of symptoms,

and the themes in this paper are limited to the theoretical terminology. One final distinction was those papers which explicitly structured their findings according to the trajectory of patients' experiences (no's 2, 5, and 12), and somewhat less explicitly (through categories) no.9. The following table lists each of the papers by title (A), and then explicates the format of each paper's findings (B), the findings themselves (C), and the authors' main conclusions (D).

Table 16 - Findings and Main Conclusions of the Included Studies

	Paper and Format of Findings - Findings and Main Conclusions
1	**A.** An exploration of life attitudes in patients with nasopharyngeal carcinoma **B.** 4 themes
	C. 1. Build the confidence to survive and learn to embrace life 2. Develop a new love for self and others 3. Reinterpret their attitudes toward suffering and death 4. Achieve life meaning by transcending their ego **D.** Patients re-evaluate their attitudes through the experience of cancer. Life and loved ones become more highly valued, priorities reassessed, and death is confronted.
2	**A.** 'Let me explain': narrative emplotment and one patient's experience of oral cancer **B.** 6 stages to adapting to the reality of oral cancer
	C. 1. Pre-cancer: 'touch wood' 2. Learning to live in 'therapeutic emplotment' 3. In limbo: holding one's breath 4. Recurrence: 'therapeutic emplotment' cont. 5. Through the mirror: the 'unspoken narrative' 6. Endings or the end? **D.** Via HPs' communications, the focus of the patients is fixed firmly on the immediate (not the future), and this acts to instil hope, and confidence in treatments. HPs help patients construct a new plot to their life – 'therapeutic emplotment' – which replaces their existing narratives. Patients collude in this, and doubt, uncertainty, and fear are confined largely to the 'unspoken narratives'.
3	**A.** Life experiences of head and neck cancer survivors: A pilot study.

	B. 4 major categories made up of 10 theme clusters
	C. 1. Treatment side effects 2. Self-image disturbance 3. Depression 4. Pain **D.** Treatment side effects – particularly eating/swallowing impairment, and pain – were cited as the most difficult aspect of the experience to cope with. Body and self image was altered due to impairments, and disrupted life. Feelings of guilt, anxiety, and helplessness were evident.
4	**A.** Coming to terms: a grounded theory of adaptation to facial surgery in adulthood **B.** Organised into a model of adaptation - 4 super-ordinate categories
	C. 1. Demands 2. Influences and resources 3. Responding and managing 4. Consequences **D.** Adaptation to facial surgery is dictated by the interaction of the demands of the situation and available resources, and is mediated by appraisal and coping. A cancer diagnosis mediates appraisal of disfigurement (requires further research). Social support and coping skills are key factors in differences in outcomes.
5	**A.** Communication and information: the experience of radiotherapy patients **B.** 9 important areas of the radiotherapy experience
	C. 1. Information regarding diagnosis 2. Preservation of hope after the diagnosis has been confirmed 3. Information about treatment options and prognostic outlook 4. Hope related to treatment 5. Information regarding the side-effects of treatment 6. Information about the personal 'costs' of treatment 7. Information about tests during follow-up visits 8. The influence of health workers demeanour on the self-esteem of cancer sufferers 9. Verbal acknowledgement by staff of the difficulties of treatment **D.** Key difficulty for HPs is that individuals' information preferences vary markedly regarding diagnosis and treatment options. Full info about short and long term side effects was desired by patients, and key to enable patients to cope with the trauma of impairments. Follow-up care was little understood. HPs' demeanour, and acknowledgement and recognition from them is important to patients coping with cancer.

6	**A.** Needing a hand to hold: Lived experiences during the trajectory of care for patients with head and neck cancer treated with radiotherapy. **B.** 1 overarching main theme, and 3 sub-themes
	C. Main theme – Needing a hand to hold Sub-themes – 1. Disruption of daily life, 2. Waiting in suspense, 3. Left to one's own devices **D.** The experience of eating problems and the experience of having cancer go hand in hand. It was characterised by disruption to life and uncertainty. A lack of the ability to access support led to feelings of being abandoned, particularly post-treatment, and fostered uncertainty. Continuous access to a knowledgeable HP throughout the trajectory was desired.
7	**A.** Lived experiences of eating problems for patients with head and neck cancer during radiotherapy **B.** 3 main themes, sub-themes, and sub-sub-themes
	C. Main theme 1 – Ability to chew and swallow/Will and desire to eat Sub-themes – 1. Experiences of change is saliva quantity and consistency, 2. Experiences of narrowness and pain, 3. Experiences of taste changes and nausea Main theme 2 – The way of life is disturbed Sub-themes – 1. Loss of the meal – loss of togetherness, 2. Paralysing tiredness, 3. Life itself is threatened, 4. The image of self is changed – shame waits round the corner Main theme 3 – Trying to see the end – to survive Sub-themes – 1. Moving between hope and despair, 2. To endure the situation Sub-sub-themes – 1. Strength comes from inside, 2. Strength comes from outside **D.** Eating problems are part of the broader cancer experience and also threaten life. There is a reciprocal relationship between ability to eat and the will/desire to eat. Impaired eating impacts seriously on daily life, and self-image, and increases anxiety. Side effects worsen progressively, dominating thinking, and cause the fluctuation of hope and despair.
8	**A.** Striking the right balance: a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer **B.** 2 main themes, sub-themes, and sub-sub-themes
	C. Main theme 1 – Patient expectations Sub-theme 1 – Global Sub-sub-themes – 1. Unexpected enormity of treatment/recovery,

	2. Expectations being surpassed by reality Sub-theme 2 – Specific Sub-sub-themes – 1. Side-effects of treatment, 2. Aesthetical outcome, 3. Recovery as a process Main theme 2 – Information influencing expectations through Sub-theme 1 – Too much information Sub-sub-themes – 1. Limits to how much info can be 'taken in', 2. Repercussions on ability to cope Sub theme 2 – Too little information Sub-sub-themes – 1. 'Missing' information, 2. Lack of clarity Sub-theme 3 – Timing of information Sub-sub-themes – 1. Knowledge gap, 2. Uncertainty **D.** Patients' expectations of their disease and treatments, and their information preferences, vary widely. Information-giving by HPs has a marked influence on the formulation of expectations. A gap exists between expectations and experience – the latter often being much worse than patients anticipated.
9	**A.** Concerns of families in which one member has head and neck cancer **B.** 5 major categories of concern
	C. 1. Cancer and its meaning 2. Social relations 3. Hospital experience 4. Treatment 5. Future placement **D.** The concerns of patients and families differ across the trajectory. Initially cancer is conceived of as serious and life-threatening. Carers' concerns are more focused around the risks and consequences of treatment, and their ability to cope. During treatment patients' concerns centre on treatment, following it they centre on the impairments' impact on their lives.
10	**A.** Communicating suffering in primary stage head and neck cancer **B.** 3 major themes
	C. 1. A self diminished by cancer (The self diminished after SCCHN: a process with many layers) 2. The fear of addiction to pain medications (Fears of cancer, fears of addiction) 3. Hopelessness and the loss of meaning in life after SCCHN (squamous cell carcinoma of the head/neck) **D.** The disruption of SCCHN to life is severe. There is a reticence to report side effects/ seek help from HPs, underpinned by fear. Losses to self and life produce negative affect – hopelessness.

11	**A.** Speech impairment in the postoperative head and neck cancer patient: nurses' and patients' perceptions **B.** 2 main themes from the patients' data, and 5 sub-themes
	C. Main theme 1 – Describing pain Sub-themes – 1. Making the pain known, 2. Numbering the pain, 3. Lack of awareness Main theme 2 – Feelings Sub-themes – 1. Frustration, 2. Persistence [There are separate findings from the nurses' data concerning their perspectives on communication and managing pain in this patient group – these are not listed here.] **D.** Patients feel a responsibility for communicating their pain needs to HPs, and strive to make their needs known. Loss of the ability to communicate is a source of immense frustration. HPs' perceived lack of awareness of/insensitivity to their difficulties can be a problem.
12	**A.** The uncanny mouth – A phenomenological approach to oral cancer. **B.** 1 overarching main theme, and 3 sub-themes
	C. Main theme – The uncanny mouth Sub-themes – 1. Experiences at treatment start – the invaded body, 2. Experiences of treatment – no escape from the wounded mouth, 3. Treatment end – the disabled mouth **D.** The mouth dominates life and thinking throughout the trajectory. 'Normality' is equated with a return to normal oral functioning. The need for support increases over time and reaches a peak after completion of radiotherapy as functional impairments reach their worst.
13	**A.** Patient delay in oral cancer: a qualitative study of patients' experiences **B.** 5 major themes
	C. 1. Symptom interpretation 2. Attribution of symptoms to cancer 3. Knowledge about oral cancer 4. Coping with oral symptoms 5. Barriers to seeking help **D.** Patients' appraisal of oral symptoms as non-cancerous is influenced by their conceptualisation of cancer and its symptoms. Cancer is rarely considered, and often diagnosis comes as a shock. Ignorance of the existence of oral cancer is linked to delayed help-seeking.
14	**A.** The process of symptom appraisal: cognitive and emotional responses to detecting potentially malignant oral symptoms **B.** Findings not presented thematically - 4 main areas of findings

	C. 1. Symptom interpretations 2. Reinterpretation of symptoms 3. Emotional responses 4. Reappraisal of emotional responses **D.** Patients interpret unusual symptoms and generate cognitive and emotional responses which influence behaviour. Initial oral symptoms are often perceived as minor, transient conditions - rarely is the possibility of malignancy considered. This is one explanation for delayed help-seeking. Reappraisal followed persistence of/change in symptoms, new info, or failure of attempts to cure it. Awareness of symptoms of oral cancer is poor.
15	**A.** The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment **B.** 5 main themes
	C. 1. The hidden experience 2. The disruption of symptoms 3. Perceived insignificance 4. Loss of self 5. Living with uncertainty **D.** The disruption of radiotherapy side effects is considerable, and symptoms worsen post-treatment. Patients play down their suffering, and distress is often hidden from HPs; there is a reluctance to seek help. Continuing impairments erode self-confidence. Uncertainty characterises the experience.

6.4.3.3 CLASSIFICATION OF PAPERS BY FOCUS

The remit of the synthesis was the experience of head and neck cancer, encompassing all aspects of this experience, including treatments and side effects. This was suitably broad in view of the reported dearth of evidence, however the topical focus of individual papers varied broadly. In order to make sense of the relationships between the papers, and how they fit together, it was necessary to organise them according to their primary focus.

The papers focussed on 3 broad areas - the experience of cancer, with differing levels of emphasis on certain aspects of the trajectory from pre-diagnosis to beyond treatment; the experience of treatments – the side effects and recovery process of surgery and radiotherapy; and the role of information. The composition of these groups is illustrated in figures 4-6.

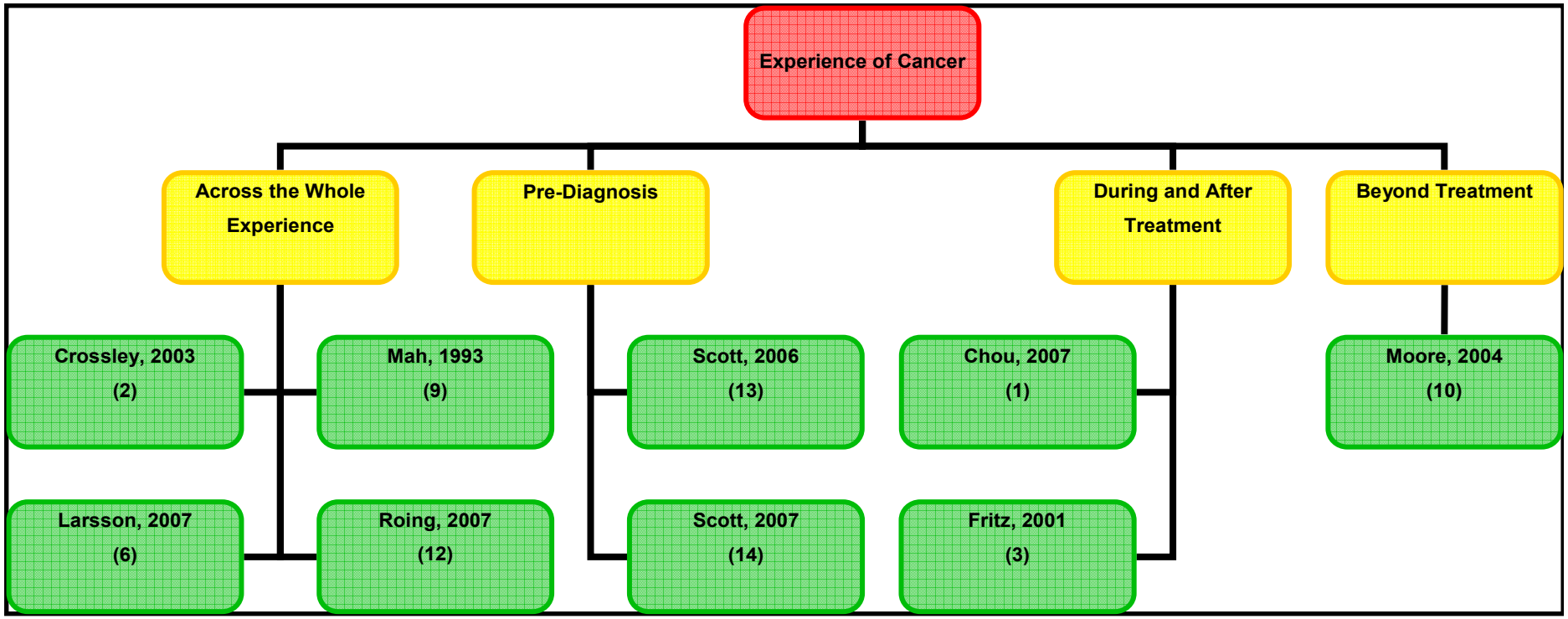


Figure 4 - Papers focussed primarily on the experience of cancer

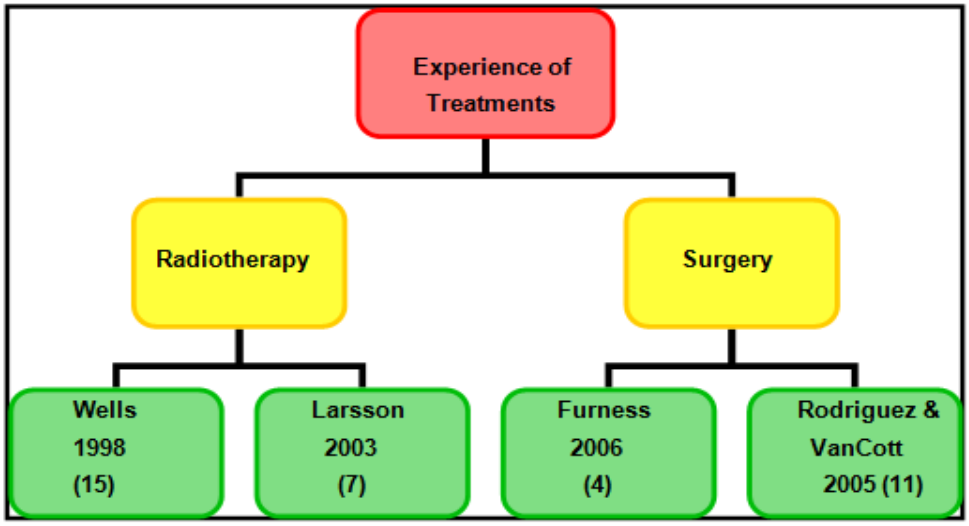


Figure 5 - Papers focused primarily on the experience of treatments

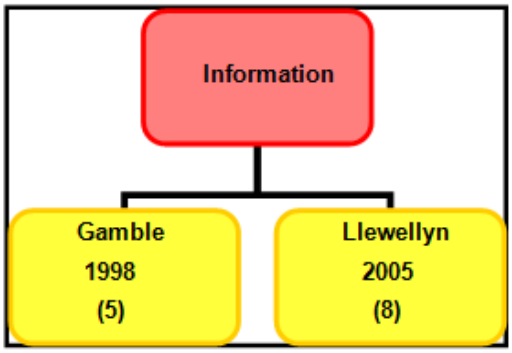


Figure 6 - Papers focused primarily on information

However, these areas were not as distinct as these diagrams imply. There was considerable overlap between the content of the papers – for example it is difficult to consider the experience of radiotherapy out-with the broader context of having cancer; and as Larsson (2007) noted in their exploration of disease- or treatment-induced eating problems, patients' encounters with these, and with cancer itself, are inextricably linked.

This overlap and reference to the wider context of living with cancer, allowed us to synthesise the findings of the whole, an approach congruent with the goal of producing a secondary interpretation; contrary to the traditional systematic review, where evidence

pertaining to a tightly-defined issue and population is aggregated, and conclusions formed.

The purpose of stage three, the scrutiny and classification of the papers' methods and findings, is to facilitate the first analytical part of the process – the relation of the papers and translation of each concept across the pool of studies. This is stage four, and is delineated in the following chapter. In this case however a further sub-plot was enacted during stage three, the examination of the original papers for references to the existence of mental images of the cancer

6.4.4 VISUAL ASPECTS OF PATIENTS' EXPERIENCES REMAIN HIDDEN

None of the papers' themes pertained to images, though patients' expectations and understandings of their experience were addressed in papers no.5 and no.8, which focussed on information. Other papers reflected on patients' initial perceptions of the cancer when symptoms first appeared - no.13 and no.14. The majority of the studies did not frame patients' experiences in terms of how they understood their cancer however, and while beliefs about the consequences of the disease were abundant in the selected studies, these were relayed more in terms of outcome (cure/death) and the impact on the patient's life. This framing of experiences was anticipated and appropriate for the included studies though as neither mental images nor illness beliefs was a distinct focus of any of the papers.

It was anticipated that some allusion to images of the cancer may be found in the raw data presented however. This expectation developed from the pervasiveness of images in the pilot study interviews, where the use of verbally-expressed figurative images was prolific as participants relayed their understandings and experiences of the cancer and treatment. The expression of images of the cancer/treatments was not confined to

specific responses to image-related questions, but peppered participants' accounts in a seemingly fluent, natural way. It was considered possible therefore that such images may be embedded within the excerpts of data on a wider range of topics. This hypothesis was not borne out by the scrutiny of the included studies however, with only one excerpt conveying any sense of a mental image of the cancer:

> "It's got no roots or anything, it was just on the surface… not cancer as such… not one that's going to spread from here there and everywhere." (Wells, 1998, p844)

This excerpt appears to illustrate an underlying image in the patient's understanding of their cancer. It is visual rather than words-based, reflecting not simply an abstract belief that the cancer is unlikely to spread, but a physical representation (or image) of the properties of the cancer which accounts for this belief – "it's got no roots." The surveying of this small sample of relevant studies does not enable any conclusions to be drawn about the extent to which imagery is embedded in patients' experiences, as these papers were not focussed on the topic, nor were the full datasets available for scrutiny, only those excerpts included in the publications could be examined. However the absence of much evidence of images is congruent with the apparently hidden nature of patients' visual knowledge of their cancer suggested by the findings of the pilot study.

6.5 CHAPTER SUMMARY

This chapter has presented the background and rationale behind the meta-synthesis of qualitative research on experience of head and neck cancer. It has outlined our approach to the synthesis, and the implementation of the first three stages of Noblit & Hare's (1988) process. Stage one encompassed defining the scope of the synthesis in terms of topic and patient population, and designing the search strategy in terms of selecting which databases to search and the search terms to use. We chose seven

databases and replicated an existing search strategy devised by Shaw et al (2004) based on three separate search strings – thesaurus terms, free-text terms, and broad based terms – in conjunction with relevant head and neck cancer-related terms. Stage two comprised the execution of the search strategy and identification of pertinent papers to create the 'bank of data' which would be synthesised. The number of papers retrieved by each of the three search strings in each database was described, and this strategy retrieved a total of 114,311 records. A four-stage process of identifying relevant papers was then enacted – title screening, abstract screening, full-text screening, and critical appraisal. Forty-eight papers were appraised by two independent reviewers using the CASP tool for evaluating qualitative research, and fifteen papers survived this process and were included in the synthesis. The third stage involved the examination of the included papers and explication of their methods, findings, and main conclusions. The papers pertained primarily to one of three aspects of the experience of head and neck cancer – experience of the disease, experience of treatments, and the role of information. These first three stages constitute the process of designing the meta-synthesis and collecting the 'data', that is the fifteen papers which have been included. The scrutiny of these papers revealed little reference to images of the cancer, satisfying the question of whether evidence of patients' mental images is present in the existing literature. The subsequent chapter will outline the execution of the final two stages of the synthesis, which are more analytical in nature – translating the findings and relating the studies (stage four), and synthesising translations (stage five). The findings of the meta-synthesis are then presented, representing a secondary interpretation of the combined study findings on the nature of the experience of head and neck cancer.

7 A META-SYNTHESIS OF QUALITATIVE STUDIES OF THE EXPERIENCE OF HEAD AND NECK CANCER – ANALYSIS AND FINDINGS

7.1 INTRODUCTION

This chapter will describe the implementation of the final two stages of the meta-synthesis process, and then present the findings. Stages four and five of the synthesis are analytical in nature, the first determining how the included studies relate to one another, and translating each of the original concepts across the pooled findings. The purpose of stage four is to identify the essential themes pertinent to the experience of head and neck cancer, by synthesising the findings of the papers. Some of the difficulties in discerning the meaning of the original concepts and translating them across the studies are outlined, alongside the novel, team-based approach to this exercise. Eleven key concepts were determined during stage four, which encompassed all of the authors' original concepts. Stage five comprised the process of reviewing, refining and synthesising these concepts until they formed a credible representation of the studies' findings overall. The findings of the meta-synthesis consist of six core themes pertaining to two categories. The first category is the context or reality of head and neck cancer, encompassing three themes – 'living and waiting: betwixt and between', 'disruption to daily life', and 'the diminished self'. The second category represents how patients negotiated the experience, incorporating three further themes – 'making sense of the experience', 'sharing the burden', and 'finding a path'. This chapter will present these themes with reference to some of the relevant literature, and reflect on the value of the synthesis.

7.2 STAGE FOUR: TRANSLATING THE FINDINGS AND RELATING THE STUDIES

Stage four required the relationships between the papers' findings to be explicated. The process of translating the concepts and relating the studies was not straightforward however. There was a degree of 'cloudiness' concerning many of the conceptual categories which meant it was more difficult to discern meaning. This section will detail the difficulties in executing stage four, and describe the translation process by which eleven key concepts – which encapsulated all of the original findings – were identified.

The assumption at the outset was that because the studies were – more or less – concerning similar things, the findings of each study would be translated into each other in a reciprocal fashion (Noblit & Hare, 1988, p38). The aim is to translate the meanings of the themes identified by each author into each of the other studies (Noblit & Hare, 1988, p31). This is a comparative process, involving the identification of conceptual or thematic similarity, or lack thereof.

It is through the translation process that the predicted mode of synthesis is confirmed or denied, in this case whether or not the relationship between the papers is reciprocal – or indeed confounding (refutational synthesis) or whether the papers are, collectively, constructive of a line-of-argument synthesis (Noblit & Hare, 1988, p38).

7.2.1 THEMATIC CLOUDINESS

It is important at this stage to be faithful to the studies' conceptual labels (Noblit & Hare, 1988, p39), and traditionally in meta-ethnography deconstruction or decontextualisation of the findings is not part of the process, though this is sometimes employed in qualitative synthesising to enable re-analysis of the study findings (Finfgeld, 2003, p900). The goal

here however was not to re-analyse the original findings, but to investigate the relationships between the concepts of a set of studies.

It became apparent during the scrutiny of the papers in stage 3 that a degree of deconstruction would be necessary to facilitate meaningful translation. A number of the studies' findings were expressed more in terms of descriptive categories than specific themes, and the labels themselves revealed very little about the content. This included findings from papers number 3 (Fritz), 4 (Furness), 9 (Mah & Johnston), 13 (Scott, 2006), and 14 (Scott, 2007). To a lesser extent, some of the themes cited by Crossley (no.2), Gamble (no.5), Llewellyn (no.8), and Rodriguez (no.11), were also somewhat ambiguous.

The use of categories was well-warranted in some of these studies. For example, the purpose of Furness's (2006) research was to develop a tentative model of adaptation to facial surgery in adulthood, and appropriately their findings were presented in model form incorporating 4 categories: 'demands', 'influences and resources', 'responding and managing', and 'consequences'. Another case was that of Scott (2007), who used existing theoretical constructs from Leventhal's Self-Regulation Model to investigate patients' experiences of discovering potentially cancerous oral symptoms, and structured their findings according to these constructs.

The 'cloudiness' of descriptive categories referred to here is perhaps best explained through comparison with specific thematic findings - table 8 provides an example using actual themes from two of the studies we incorporated.

Table 17 - Example of cloudy versus clear thematic labels

A: The 'Cloudy' Case – Fritz, 2001 (no.3)	**B: The 'Clear' Case – Roing, 2007 (no.12)**
4 major categories	1 overarching main theme, 3 sub-themes
1. 'Treatment side effects'	Main Theme – 'The uncanny mouth'
2. 'Self-image disturbance'	1. 'Experiences at treatment start – the invaded body'
3. 'Depression'	2. 'Experiences of treatment – no escape from the wounded mouth'
4. 'Pain'	3. 'Treatment end – the disabled mouth'

The contrast between these two cases is readily apparent. The labels adopted in Case A are purely descriptive, citing areas of the findings, but not hinting at the shape or form these take (with the arguable exception of category no.2). For example, there is no characterisation of the impact or importance of treatment side effects (no.1) and, other than the fact that they constitute an element of patients' experiences; no meaningful inference can be drawn from this label.

Case B includes a descriptive aspect in their themes, explicating the stage of the trajectory to which each concept refers. However they also, crucially, incorporate statements reflecting the meaning of each theme – 'the *uncanny* mouth', 'the *invaded* body' etc – characterising the types of experiences uncovered. This more specific labelling, grounded in the meaning of each concept, is obviously far more amenable to translation in its original form – the preferred strategy in meta-synthesis to maintain the integrity of the individual studies (Noblit & Hare, 1988).

In this context, it was decided to undertake a degree of deconstruction of the papers' findings in terms of identifying the components of each theme, with the goal of enhancing

our understanding of the meaning of the original concepts – not as a re-analysis of the paper.

7.2.2 DECIPHERING MEANING

Each of the concepts was deciphered for meaning according to the aspects of the experience to which it pertained. The process of deciphering meaning involved photocopying each paper and pasting the findings onto sheets of A4 with a margin left on one side. Systematic reading of each concept enabled the significant metaphors to be drawn from each and noted in the margin, using the original terminology where appropriate.

The breaking down of concepts in this way in fact constituted the beginning of the translation process As components of each theme were identified, it became evident to which other themes they reciprocated, and where shared meanings existed between the papers.

As reciprocal relationships became apparent judgements were made about the appropriateness of one term over another, or indeed importing a different term altogether. The application of such judgement is noted by Noblit & Hare (1988, p39):

> "There are, of course, a number of technical decisions to be made as directly translated into another account, these reciprocal translations may reveal that the metaphors of one study are better than those of others representing both studies, or that some other set of metaphors, not drawn from the studies, seems reasonable."

7.2.3 IDENTIFYING THE KEY CONCEPTS

In their original publication of the meta-ethnography, Noblit & Hare (1988, p25) promote the exploration of other approaches to synthesising research, citing that their method is but one potential mode to address it. As indicated in the background section of this chapter, a proliferation of approaches has since been presented (McCormick et al, 2003, p934). With this in mind, it was considered that a degree of initiative or creativity could be applied when putting each of the stages in to practice, and this is particularly true of this next phase.

In order to clarify the key concepts which existed encompassing all the original concepts, we enacted a 'cut and paste' exercise. Using individual cards made up for each theme, including the short notes on meaning produced during the previous phase, two of the research team went through a systematic process of reading and tentatively organising the concepts into groups according to shared meaning or frame of reference, and hence 11 key concepts were recognised.

The sufficiency and validity of these tentative concepts was then investigated in two ways. Firstly, another member of the research team carried out the cut-and-paste exercise in reverse – beginning with the 11 key concepts, and attempting to organise relational themes accordingly. Concurrent to this, the papers were re-scrutinised to ensure the key concepts identified 'fit', and accurately represented the findings.

An initial consensus rate of 82% was achieved between the independent reviewers, and some minor regrouping required before a suitable 'fit' was achieved. Examination of the original texts satisfied that each of the papers' concepts was encompassed within one of the key concepts. The issue of synthesising themes pertaining to different aspects of the overall experience did not pose a problem for translation because, as Britten et al (2002, p211) note, the goal is not the translate each of the findings of one paper into

each of every other paper, but to ensure every finding is synthesised with relational ones, and that all of the concepts are included within the range of key concepts.

7.3 STAGE FIVE: SYNTHESISING TRANSLATIONS

Once the eleven key concepts had been derived through translating the findings of the studies, the final phase of analysis, the process of exploring, refining and reviewing the concepts – synthesising translations – commenced.

This stage is interpretive, analytic, and difficult to describe meaningfully in a procedural format (Britten et al, 2002, p211). That said, an attempt to describe the process follows. The tentative concepts were read and re-read, and five of the preliminary concepts merged with the others. The enlarged groupings were then refined and re-structured until they were deemed to be an accurate and credible reflection of the synthesised findings. Reference to the original texts was a continual part of this process.

Great debate ensued surrounding the defining labels of each concept because, as Noblit & Hare conclude (1988, p82), the value of the synthesis lies in its intelligibility to the intended audience. Therefore, it was considered important to maintain a firm conceptual grounding in the language of patients' experiences.

Discussion of the suitability of various conceptual labels, their comprehensiveness, fittingness, and clarity, resulted in the fourth considered co-constructed set being settled on. Thus the synthesised translations eventually produced six refined concepts:

1. 'Living and waiting: Betwixt and between'
2. 'Disruption to daily life'
3. 'The diminished self'
4. 'Making sense of the experience'

5. ‘Sharing the burden’
6. ‘Finding a path’

The first three concepts remained close to some of the original themes, for example ‘living with uncertainty’ in Wells (1998), ‘disruption of daily life’ in Larsson (2007), and ‘a self diminished by cancer’ in Moore (2004). Concepts 4, 5, and 6 however required more innovation as suitable metaphors were not evident in the sample.

‘Finding a path’ is somewhat distinctive as it is a concept which reflects an element of refutation between the studies. We would contend that the relationships between the papers are extensively and overwhelmingly reciprocal, however in the process of refining the concepts it was realised that some of the separately translated findings were in fact refutational of others. As Kearney (2004) points out, it is important to:

> “…counter our understandable tendency toward objectivist over-simplification and acceptance of the majority view as true. We seek to develop methods in which alternative experiences and interpretations are revealed rather than neutralised, and… differences must be sought and honoured.” (Kearney, 2004 – Cited in Thorne, 2004, p1352)

Therefore the restructuring of the concepts took into account this incongruity, and ‘finding a path’ reflects and explores this divergence of perspectives beyond the experience of head and neck cancer.

7.4 FINDINGS: A SECONDARY INTERPRETATION

7.4.1 OVERVIEW OF THE FINDINGS

Six core themes emerged from synthesising the key concepts, and these pertained to two categories – the context of head and neck cancer, and negotiating the experience – as illustrated in figures 7 and 8 below. The context of head and neck cancer, the reality of living with cancer and enduring the treatments, was expressed in three themes – 'Living and waiting: Betwixt and between', 'Disruption to daily life', and 'The diminished self'. While 'Making sense of the experience', 'Sharing the burden', and 'Finding a path' described how patients negotiate the experience, with patients as active interpreters and constructers of their experience, rather than as passive recipients of it. The remainder of this section will explain each of these themes in turn.

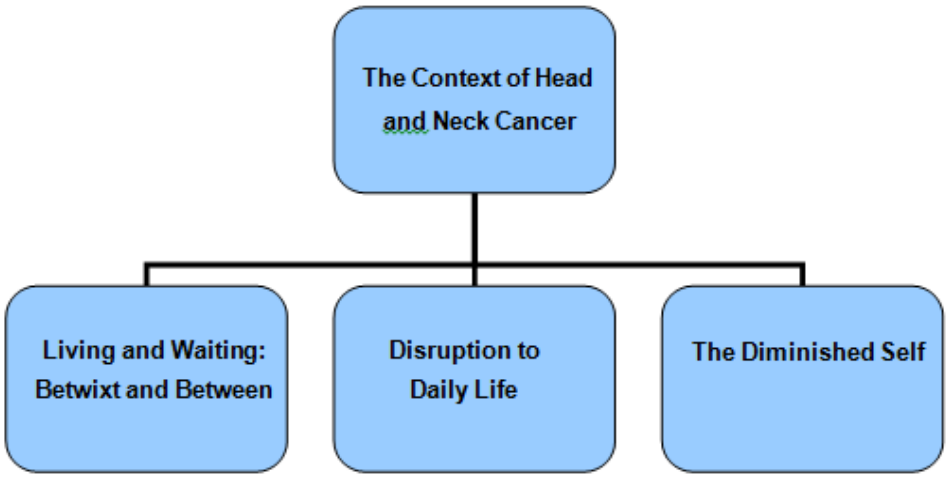


Figure 7 - Elements of the context of head and neck cancer

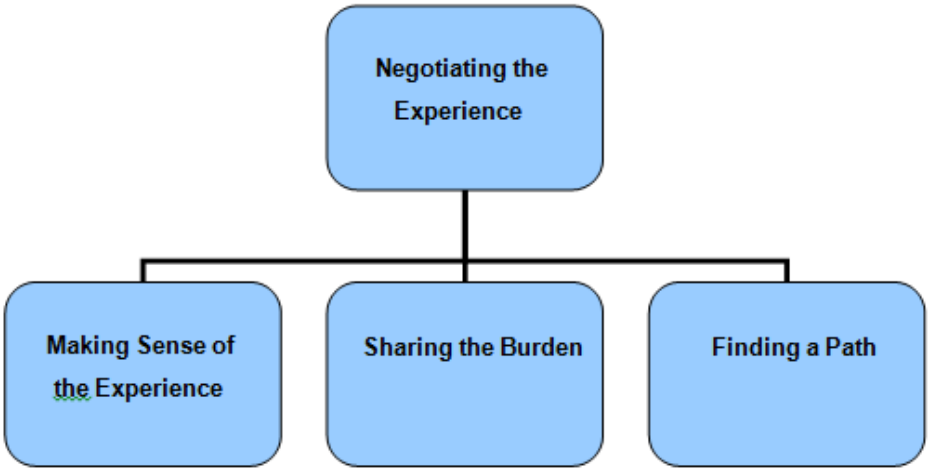


Figure 8 **- Elements of how patients negotiate the experience of HNC**

7.4.2 'LIVING AND WAITING: BETWIXT AND BETWEEN'

Uncertainty characterises the experience of cancer from the first appearance of symptoms which are recognised as threatening, to beyond the completion of treatment. The predicted narrative of the individual's life has been interrupted, and what will take its place is indeterminable.

Hope and despair tussle for dominion, and the trajectory of illness is punctuated by numerous periods of waiting. These periods of waiting in suspense exacerbated anxiety, and corroded hope.

> "The waiting is the worst part of this whole business – what is going to happen to me?" (Wells, 1998, p845)

The gap between diagnosis and commencing treatment can be agony to endure, as patients are desperate to start 'fighting' the cancer.

> "What's happening with my tumor now that they have to wait 2 more weeks? Is it growing? Do they treat those patients they believe they can cure first?" (Larsson, 2007, p329)

Patients are in a fluctuating state of limbo, in suspense, waiting for some kind of certainty to be restored – there is a loss of security and loss of the future. The uncertainty does not end with the news the patient is disease-free afterwards. The threat of recurrence looms large, and it is realised that a nice neat line cannot necessarily be drawn under the whole experience:

> "The truth is… I still don't know whether I'm cured. Nor will I know for weeks, or months, or possibly years." (Crossley, 2003, p444)

In an attempt to combat this uncertainty, patients interpret their experiences – everything from the length of delay before starting treatment, to the appearance, change in, or worsening of side effects is fair game as they strive to anticipate the future.

7.4.3 'DISRUPTION TO DAILY LIFE'

This theme represents the reality of the having cancer, and in particular the disruption of the treatment period and beyond. The patient's life is disrupted in a three-fold manner – physically, emotionally, and socially.

The normal daily routine and equilibrium are disturbed first by the diagnosis of cancer where one is thrust suddenly from the world of the healthy into the world of the sick. Cancer is experienced as threatening one's life, and patients feel this as a loss of control. They may think about their own mortality for the first time, and fear and anxiety characterise this period.

> "My major concern right now is death not my voice not my pain."
>
> (Mah & Johnston, 1993, p385)

When treatment begins the patient adjusts to a new normality, work is replaced with a routine of trips to the hospital, and as treatment progresses and side effects worsen, more and more aspects of daily life are disrupted by physical impairments resulting from surgery or cumulative radiotherapy.

Eating problems dominate, and physically this involves a thickening and lack of saliva, changes to taste, pain in the mouth and throat, and a feeling of narrowness in the throat – all of this impairs the ability to chew and swallow food. The fatigue caused by radiotherapy is exacerbated by this lack of nutrition.

> "You can't imagine this tiredness. You are so incredibly tired… it's paralysing. You can't stay awake." (Larsson, 2003, p567)

The act of eating is dreaded and the pleasure from it is lost. Patients become reluctant to eat for fear of the consequences – pain, choking, unpleasant tastes, or simply the sheer tedium and frustration of having to persevere and being repeatedly disappointed.

> "The worst time of the day is when I eat… it is really tough… nothing tastes good anymore. It is hard to eat… it is absolutely the worst time of the day. Yet you have to eat… it just takes so long." (Roing, 2007, p305)

Meal times are fraught with anxiety and no longer a social occasion. The struggle to eat and unpleasant physical consequences – choking, coughing up thick saliva, perhaps

dribbling or wincing in pain – produce shame and embarrassment, and a desire to eat alone - patients withdraw from their social life, and even from their familial one.

After treatment is completed side effects reach their peak, and ongoing physical dysfunction continues to disrupt daily activities of living. Patients may have to adjust to permanent impairments or visible disfigurement, and this and the fear of recurrence means that their previous roles, social life, and equilibrium may never be restored to their pre-cancer state.

7.4.4 'THE DIMINISHED SELF'

A sense of loss emerged strongly from the synthesis. This theme is linked strongly to the disruption of daily life, and during the period of having cancer and undergoing treatments, patients experience losses of the functional, social and existential kind.

From the initial diagnosis of cancer the patient's self-image begins to change. The threat to life and loss of control this entails challenges the patient's identity and their expectations of their life (biographical disruption – Bury, 1982). The person becomes a patient, inhabiting the new and foreign world of the sick. Their emotional world is changed - fear, anxiety, and uncertainty dominate – and they are newly dependent on health professionals.

The functional impairments caused by treatments further erode self-image and self-confidence. The self is diminished – physical problems are constant reminders of the cancer and the lack of normality, and after the end of treatment draw attention to the danger of recurrence:

> "…you know every time I feel around in my mouth and feel that part of my tongue that's gone I feel so afraid it (the cancer) will come back. That missing part of my tongue is a constant reminder. That is the pain of cancer." (Moore, 2004, p58)

Difficulty speaking and eating can undermine one's sense of self and attack self-esteem. The former was particularly salient for writer John Diamond, whose work and self-image was centred on quick-witted commentary on life; while the indignity of the inability to eat properly was captured by another patient:

> "I am not now the person my friends befriended, my wife married. I am not me anymore." (Crossley, 2003, p444)

> "I have a mouth to eat with and you eat by yourself. I have done that all my life and I will continue to do so." (Larsson, 2003, p567)

The obviousness of such impairments, along with changes in appearance, can result in social withdrawal, due to either a loss of enjoyment or a desire to conceal them, and thus losses take a social form as well as a functional one:

> "I am really very sociable, yet it is just too difficult to speak sometimes… and people don't hear… and I have to constantly think about how I will make myself understood." (Roing, 2007, p304)

> "I didn't want anyone asking me uncomfortable questions at the time… I felt I couldn't go out, people I knew I'd see and I didn't want to have to explain, that sort of thing." (Wells, 1998, p845)

For many patients the feeling of being 'diminished' is a temporary state, functional losses may repair in time, and while life beyond cancer may not return to normal, the patient adapts and accepts the changes in their life and views it as changed rather than diminished. Not so for others, there was a clear sense of viewing the future as less than it was meant to be, and whose life beyond cancer is marked by disappointments and frustration at the losses incurred. This is explored further in theme six – 'finding a path'.

7.4.5 'MAKING SENSE OF THE EXPERIENCE'

Patients continually strived to make sense of what was happening to them. They were far from passive recipients of information; instead they actively interpreted and constructed the meaning of their cancer - a finding congruent with Vanderford et al's (1997) view of the patient in their advocacy of narrative research in the field of health communication.

The information received from HPs was a key in this, and by interpreting this and other information – prior beliefs, symptoms, side effects, and the care they receive - patients form an understanding of what is happening to them.

Accordingly patients developed fears and expectations specific to their situation, and these impacted on their emotional and behavioural responses to the disease. For example the perception of cancer as a serious, potentially fatal disease rendered disfiguring facial surgery more retrospectively acceptable:

> "…I personally think the cancer issue is far greater than the facial disfigurement… I actually don't give a toss to what I look like because I'm alive, and I just think the issue of cancer returning and doing its worst, it's a far bigger issue than how you look." (Furness, 2006, p460)

Side effects of treatment were also perceived as part of the process and insignificant next to the threat of cancer, and so they were endured without seeking help from HPs.

There were of course patients who wanted to limit the amount of information they received or took on board, and who were reluctant to delve too deeply into the potential consequences of the disease or treatments:

> "I only needed to know what was needed to be known. Because if I'd had too much information you would have found me in the corner with a vodka bottle." (Llewellyn, 2005, p188)

However, this does not necessarily mean these patients did not interpret their situation and form judgements about it, simply that they shied away from certain types of information.

Essentially, in the context of a body which is changed and unpredictable - in terms of both the cancer and the way it responded to treatment - patients were striving to anticipate the future and negate the uncertainty inherent to the experience.

7.4.6 'SHARING THE BURDEN'

Developing a connection with health professionals is vitally important at a time when patients are feeling vulnerable, perhaps bewildered and frightened, by the new world they have been thrust into.

> "From the very beginning you need someone who sees you through. You need someone who asks how it is. Do you manage? What do you wonder about? You feel so incredibly deserted and vulnerable." (Larsson, 2007, p330)

They are reliant on HPs for information, guidance, and reassurance and this feeling of dependency contributes to the vulnerability. Failure to acknowledge and address patients' concerns threatened trust and the patient's sense of self-worth:

> "In the hospital I felt I was being practised on because I asked the doctor what he was looking for and he did not answer me. I looked in the computer machine and I could see something there but I did not know what". (Mah & Johnston, 1993, p385)

Conversely, positive experiences of being valued by HPs made a deal of difference, and faith in the HPs fostered hope and confidence in the treatments:

> "It is quite important… the way I felt I was cared for by everybody… It is worth a lot… it really helped me." (Roing, 2007, p304)

> "…The confidence that was inspired… it was very reassuring… this was a God send, a lifeline, from what I was going through…" (Gamble, 1998, p157)

There is a great need to feel acknowledged by HPs, both as a person and as one who is suffering, and to have their struggle recognised. Perceived dismissal of stated difficulties communicated a lack of understanding, and reinforced a sense of isolation:

> "And when I talk about dry mouth the radiation doctor said, 'Oh, you'll get used to that'. He has no idea what this dry mouth is. None of them do." (Fritz, 2001, p11)

Patients strived to communicate their needs and experiences to HPs, as a way of legitimising their suffering. However they were also selective about what they chose to

disclose and seek help for, and distress was often hidden – for example the difficulties of coping with treatment side effects was often played down as patients conceived of these as minor:

> "You don't like asking for things because you think it's silly… you feel it's minimal, you know, it's only feeling sick, like a slight headache, so what, or you feel tired, so what, they're only minimal things… the radiotherapy's dealing with the cancer, cancer's the big thing, having a headache, not sleeping, they're minor things so you don't want to say anything about that." (Wells, 1998, p845)

Patients had a clear need for a supportive and guiding relationship with health professionals, and this need appeared least met following the completion of treatment when side effects, functional impairments, and anxiety linger, but the security of regular contact with HPs has been withdrawn.

> "After that you were released from the hospital, you were all alone just knowing that you would get an appointment for an x-ray and that they would be in touch. But then you had thousands of questions…" (Larsson, 2007, p330)

7.4.7 'FINDING A PATH'

This final theme reflects an element of refutation between the studies, or at least a divergence in experiences more profound than detected in any other areas. 'Finding a path' refers to the way in which patients characterise life beyond head and neck cancer, their endeavour to look to the future.

It was evident from the studies that going through cancer often produces some alteration in one's perspective on life. Congruent with the experience as biographical disruption

(Bury, 1982), the future one had expected is changed, or revised, and there appeared to be two core paths which patients took – viewing the future as changed, or as diminished.

A diminished future was characterised by having to live with several losses resulting from the experience. Permanent or lingering functional impairments continue to disrupt lifestyle and daily life – eating, working, relationships and socialising are all impeded – and patients have to live with a frustrated desire to 'get back to normal', normality being defined for many in terms of normal functioning.

> "I just feel I want to have order in my mouth… so that I can talk and eat…" (Roing, 2007, p305)

The emotional turmoil brought on by the experience can also result in one feeling diminished - loss of security (in one's body and the future), mortality salience, anxiety and the fear of recurrence, alienation, and a lack of support equal a future which is significantly less brighter than before.

> "But you know what, I feel cheated by life. I have worked so hard for everything I have… …You have nothing if you don't have health. I feel robbed of the security of knowing I am healthy. I thought this was my time. A time for me. I have lost so much time in life. Time I can't make up for." (Moore, 2004, p61)

The patient's perspective is altered, and emotional recovery from the whole experience may take a long time.

The second route through cancer is one of adapting to a changed future, but one that is not viewed as diminished. Key aspects of this appear to be maintaining hope, taking an active role in tackling difficulties, finding meaning in the experience, and coming to terms with one's own mortality.

> "What I valued before was how to gain both fame and wealth, but after I became sick, I started to think about death; death is unavoidable. You have to accept it when the time comes! It is always like that. Although life can be mostly under one's control, it will not always be what we expect." (Chou, 2007, p321)

These patients' perspectives on life were also altered by the experience, but in a way that enabled them to find benefits from going through it – for example in terms of realising the value of their family, the value of their own life, and embracing the future.

> "I was losing an eye, I was losing a part of my face, but I was alive, I still had a life, I still had a wife, I still had my friends, I still had a family, we were just moving on, it was just one of those things." (Furness, 2006, p459)

7.5 SUMMARY AND PLACE OF FINDINGS

This chapter has presented the findings of a meta-synthesis of the themes of fifteen papers pertinent to the experience of head and neck cancer. The six synthesised themes represent what appear to be core elements of the experience of head and neck cancer:

- The penetrating uncertainty of living with the disease, where the future is indeterminable and the patient is periodically in a state of suspense ('living and waiting').

- The disruption to the patient's mental equilibrium, physical functioning, and social life – particularly when treatment side effects take their toll ('disruption to daily life').
- The temporary or longer lasting existential and social losses – the changes to self-image and self-confidence invoked by functional impairments and the impact of these ('the diminished self').
- Patients appeared to be actively striving to make sense of what was happening to them, interpreting a range of information to comprehend their situation and develop expectations about outcome ('making sense of the experience').
- The importance of a supportive relationship with health professionals was emphasised – their role crucial in instilling hope, maintaining self-worth, and counteracting patients' vulnerability ('sharing the burden').
- Finally the character of life beyond head and neck cancer – a changed future, or a diminished one ('finding a path').

The next part of this chapter will attempt to contextualise the findings of the meta-synthesis in terms of some relevant existing theory regarding patients' experiences – the 'liminal' nature of the experience of cancer, loss of self and the biographical disruption of illness, and the importance of the therapeutic alliance. The penultimate section of this chapter will then reflect on the potential value and limitations of the synthesis.

7.5.1 LIMINALITY AND 'LIVING AND WAITING', 'FINDING A PATH'

The concept of 'liminality' as characterising the experience of cancer was proposed first by Little et al (1998). The experience was liminal in the sense that the diagnosis of cancer alienates the patient from the security of their concepts of themselves and their lives. The lingering uncertainty over the future, increased mortality salience, and persistence of the cancer label mean that even once treatment is complete the person is

in a sense 'betwixt and between' - neither healthy as before, nor sick, rather inhabiting a space between the two, where life is precarious and the unpredictable trajectory of the illness means one is continually under threat of recurring ill-health. The patient's previous understanding of the world and life becomes redundant, they cannot return to it; their self-concept, awareness of their body and mortality is altered, and they may feel themselves apart from those who do not share similar experiences (Little et al, 2000).

This sense of uncertainty, of occupying the precarious space between sickness and wellness, was reflected in the theme 'living and waiting'. Living with head and neck cancer appeared to entail periods of being in a state of suspense, enduring continued ambiguity and a loss of security over the future even far beyond treatment completion. This kind of pervasive and lasting uncertainty has been reported consistently in other cancer populations, affecting patients and their partners throughout the diagnosis and treatment period and beyond (Shaha, et al, 2008; Harrow et al, 2008b). The estrangement of the patient from their previous concepts of self and life, and the significant changes which occur, are also reflected in the theme 'finding a path', where the patient's perspective on the future is rendered different through the experience.

7.5.2 CHARMAZ'S LOSS OF SELF AND 'THE DIMINISHED SELF'

In her seminal work on the concept of loss of self as part of the suffering endured by patients with chronic illnesses, Charmaz (1983) considered the self as essentially a social entity:

> "That is, the self is developed and maintained through social relations" (Charmaz, 1983, p170)

The basis for Charmaz's work was an extensive qualitative study of 73 patients with various chronic illnesses. The dominating feature of these interviews was an overwhelming

sense of loss, where existing images of self are discredited in the mind and positive alternatives not forthcoming, hence the centrality of the loss of self concept. It was noted however that those who had observed improvements in their situation appreciated certain benefits from their trials with chronic illness, such as increased self-awareness (Charmaz, 1983, p191), which supports the posited temporary nature of diminishment for some HNC patients.

Whether or not cancer should be defined as a chronic illness is a different debate (Charmaz did include cancer patients in her sample), as while certain hallmarks of the experience are shared with that of living with a chronic condition, it has been argued that there are significant areas of disparity too (Tritter et al, 2002).

For head and neck cancer patients, changes to body- and self- image, primarily due to surgical disfigurement, have been well-documented and explored in relation to quality of life and psychosocial difficulties (Dropkin et al, 1999; Rumsey et al, 2004). Sharing Charmaz's contention of the self as a social entity, the concept of diminished self outlined here is a self heavily marred by functional impairments which impact upon social relations, and changes to fundamental existential beliefs concerning identity and one's role in the immediate, familial, and broader social contexts.

7.5.3 BIOGRAPHICAL DISRUPTION AND 'LIVING AND WAITING', 'DISRUPTION TO DAILY LIFE', AND 'THE DIMINISHED SELF'

A second relevant theory emanating from the study of people with chronic illnesses, is Bury's (1982, cited in Lawson, 2003, p25) 'biographical disruption', which though predating it, encompasses the feature of loss of self advanced by Charmaz. The illness is viewed as a major disruptive event which challenges assumptions about one's current and future life trajectory and one's self. Part of this disruption is a change in awareness of

one's own mortality, and the dominance of bodily symptoms and impairments in day-to-day life. The reality of life also undergoes changes as social relations and physical capacities are undermined.

The concept of biographical disruption can be regarded as encompassing 'living and waiting', 'disruption to daily life', and 'the diminished self'. There was some debate around whether these three themes should be subsumed into this existing construction. However as mentioned earlier, in our deliberation over suitable 'labels' for the themes the necessity to maintain the comprehensibility of the synthesis to the intended audience (Noblit & Hare, 1988, p82) guided the decision to avoid removing the concepts too far into the abstract from the plain reality of HNC patients' experiences.

7.5.4 THE DIVERGENCE WITHIN 'FINDING A PATH'

Patients' perspectives on life beyond treatment for head and neck cancer diverged crucially in terms of whether the future was conceived of as simply changed, but not devalued, or as diminished. Congruent with the inability to return to one's pre-cancer state cited previously in this section (Little et al, 1998), the manner in which patients viewed the future was altered, and the stark contrast of these two perspectives raises the question of whether there are differences in patient or clinical variables which may relate to these.

However themes from several papers were synthesised to produce this theme, and combined with inconsistencies in the reporting of patient and disease factors across the group, it was not possible to discern any such distinctions. That said, two of the papers instrumental in the development of this theme presented opposing conceptions of the future (Chou et al, 2007; and Moore, Chamberlain, & Khuri, 2004), and their samples differed in terms of cancer severity and stage of trajectory – the former sample

comprising patients with advanced (stage 3 and 4) cancers undergoing treatments; the latter patients with early (stage 1 and 2) cancers ranging from recently diagnosed to survivors of several years. The more positive perception of the future was relayed in the study involving patients with more advanced cancers, and though no real conclusions can be drawn from comparing these disparate, unrelated studies, this is interesting to note.

It may be that there are no predicating factors which render a patient inclined toward a more positive or negative post-treatment perspective. Research into other psychological outcomes of illness has failed to detect such distinctions between different groups, for example fears of recurrence among head and neck cancer patients have not been linked meaningfully to demographic, disease, or treatment variables (Llewellyn et al, 2008; Rogers et al, 2010), and this reinforces the complexity of the individual's response to the disease and the impact it has on their life.

7.5.5 THE THERAPEUTIC ALLIANCE AND 'SHARING THE BURDEN'

The concept of the therapeutic alliance emerged from the psychotherapy literature, and has since been applied to patient-clinician relationships in a range of settings. Street Jr. et al (2009) characterise a strong therapeutic alliance as a relationship of mutual trust and respect which promotes in the patient a sense of security and of being cared for. This is fostered by satisfactory information-giving, attentiveness to patients' concerns, and an empathetic disposition.

'Sharing the burden' represented the need for head and neck cancer patients to develop a supportive, trusting relationship with clinicians, and to feel valued and understood, and this resonates strongly with the notion of a therapeutic alliance. The quality of the patient-clinician relationship may influence multiple outcomes such as patient satisfaction with care (Fuertes et al, 2007), emotional well-being, and patients' inclinations to seek

information (Neumann et al, 2007), which may be of particular relevance in the context of HNC where distress may be hidden from health professionals and patients appear to lack support following completion of treatment.

7.6 STRENGTHS AND LIMITATIONS OF THE SYNTHESIS

As McCormick at al (2003, p936) contend, the conclusions of this synthesis should not be regarded as reflecting a greater 'truth' than individual studies by merit of being based on a larger set of data, but rather as a secondary interpretation of the authors' interpretations, considering and conceptualising the original studies in new ways. The nature of qualitative synthesis after all is interpretive (Noblit & Hare, 1988, p11), not about establishing a positivist, objective truth. Certainly a different researcher approaching the synthesis may produce a different interpretation, but then this is true of all qualitative research where knowledge is regarded as relative and constructed. However it is hoped that the systematic nature of the process and the team-based approach to this synthesis may strengthen the credibility of the findings, as the findings are derived from the collective interpretations of all four researchers, which may be considered one form of 'triangulation' (Diefenbach, 2009).

The potential value of the meta-synthesis is that it enhances the accessibility of the qualitative research on head and neck cancer patients' experiences to clinicians. The broad distribution of these studies across the literature, and the current inadequacies in the indexing of qualitative work mean that access to a number of studies may be difficult. Furthermore, individual small-scale qualitative studies are often criticised for their specificity. By drawing together a number of studies to identify core concepts which appear to transcend the different contexts and patient groups involved, the findings of this metasynthesis therefore pertain more generally to the head and neck population and may be more relevant to clinicians.

Although some qualitative researchers would criticise the decontextualisation of qualitative findings , as outlined in the previous chapter, we would argue that common threads of experience do exist and may transcend contextual boundaries. In the context of health services research where applicability is key, enhancing the accessibility and applicability of qualitative work is essential if it is to have a real impact on policy and clinical practice. While purists emphasise the uniqueness of experiences to the point where nothing is shared beyond tightly defined patient populations, the relevance and impact of their findings will remain limited. Delineating those transcendent features of experience however may enable qualitative work to play a more significant role in informing the care and support that patients receive.

There are several potential criticisms of this synthesis. The exclusion of papers on the grounds of quality is a contentious issue, and as was reported in the previous chapter, resulted in some data-rich papers being excluded, despite the apparent congruence of their findings with other work. A more inclusive approach may have been justifiable. However, given that the focus of the analysis was the authors' original concepts – and not the raw data itself – it was considered reasonable that sufficient information and rationale be provided as to how they developed these concepts to give a measure of trustworthiness. A lack of data presented, and the inadequacy of the accounts of how the data was analysed in some of the papers meant that such trustworthiness was less assured, and these were the chief factors in the exclusion of papers.

The broad scope of the synthesis, and the inclusion of studies with mixed samples of HNC patients is another limitation, as finer distinctions in the experiences of these sub-groups were not detected. This reflects a tendency on the part of researchers with this population to aggregate different head and neck groups into mixed samples, perhaps due to the comparative rarity of these cancers and the similarity of the many of the

functional difficulties faced by different sub-sections of this population. A greater number of site-specific qualitative studies may enable comparison of the issues faced by different sub-groups to identify any distinct difficulties.

7.7 CHAPTER SUMMARY

This phase of the PhD research study had two aims: 1) to examine existing qualitative research with HNC patients for evidence of mental images, and 2) to assimilate and draw together the findings of existing studies on patients' experiences of HNC to provide a context in which to consider the role of mental images of the cancer, by producing a secondary interpretation of the combined findings. Utilising a three-pronged search strategy, over forty relevant papers were retrieved. This number of papers surpassed our expectations, confirming the widely dispersed nature of qualitative work. However many of the studies were not considered to be of a good enough standard to be included – only fifteen surviving quality appraisal – suggesting that while a pool of qualitative research with this patient group does exist, there are issues of quality or credibility concerning many of the studies. Scrutiny of the study findings revealed that reference to mental images of the cancer was almost entirely absent. Guided by Noblit & Hare's (1988) five-stage meta-ethnography process, we took a team-based approach to the synthesis, the four members of the research team contributing to the design and implementation of each stage, collaborating to produce the findings in the form of six core themes. The reality of living with head and neck cancer was characterised by the themes 'living and waiting', 'disruption to daily life', and 'the diminished self'; while patients coped with the impact of their disease by 'making sense of the experience', seeking a supportive relationship with health professionals ('sharing the burden'), and facing a changed future beyond HNC ('finding a path'). These themes are inter-related and concur with some of the existing theories around patients' experiences of illness, and these inter-relationships have been delineated in this chapter. The findings of the meta-

synthesis provide a context in which to consider how both mental images of the cancer and images embedded in language may be important in patients' experiences of the disease. There is a great degree of resonance with some of the findings of phase three of this PhD, the larger qualitative study which is reported in the subsequent two chapters. This was particularly evident in terms of the uncertainty of the experience ('living and waiting'), and patients' active endeavouring to make sense of their situation and predict their future, counteracting this uncertainty ('making sense of the experience'). This symmetry is explored in the final discussion chapter which proposes that mental images function as one facet of patients' attempts to understand their disease.

8 THE LONGITUDINAL STUDY – METHODS, SCOPE AND RATIONALE

8.1 INTRODUCTION

The pilot study of this project explored head and neck cancer patients' mental images of their disease and found they played an important role in patients' understandings of their cancer. Patients' conceptions of their treatments were also heavily characterised by images embedded in language (visual concepts) , and the perceived action of these induced changes in the mental image of the cancer accordingly. The previous chapter described the experience of head and neck cancer by way of a meta-synthesis of the findings of fifteen published qualitative studies. This chapter will recount the background and methodological design of the third and final empirical phase of the project, a larger qualitative study informed by the findings of phases one and two.

The aim of this study was to further explore the role of images – both mental images and visual concepts – in patients' broader understandings and experiences of the disease and its treatments; to build on the relevant findings from the pilot study and meta-synthesis. Twenty-five head and neck cancer patients were recruited to take part in a longitudinal research study comprising two semi-structured interviews – one during the early stages of treatment, the other some months after treatment completion. This chapter will explicate the rationale behind this design, the sampling strategy and difficulties in recruitment, the data collection process in terms of the conduct of the interviews, and the approach to analysing the data in this study. The findings are presented subsequently in Chapter 9, and an integrative account of the collective findings of all three empirical phases, together with the potential theoretical, methodological and clinical implications, is then provided in Chapter 10.

8.2 RATIONALE FOR THE LARGER LONGITUDINAL STUDY

The findings of the pilot study suggested three potentially worthwhile avenues to explore in the larger study, which were outlined in depth at the close of Chapter 5. Briefly, the identified options were as follows:

1. Focus on the origins of patients' mental images of their cancer. Combining audio-recordings of diagnostic consultations with patient interviews to investigate the impact of health professionals' use of images (both material clinical images and through visual language) on patients' subsequent images of their cancer.
2. Investigate the congruence of patients' and partners' mental images of the cancer. Interviewing couples to establish disparities in beliefs and mental images of the cancer, and exploring how this links to their experience of the disease.
3. Focus on the development of patients' understandings and images of the cancer and treatments over time. Broaden the focus to include greater attention to the role of visual concepts embedded in language as well as perceived mental images. Interviewing patients at different time points to explore how their understanding of what is going on inside their body evolves.

The substantial ethical and practical issues surrounding options one and two (explicated in Chapter 5), together with the novelty of a longitudinal design, and a desire to retain the focus on the experiences of the head and neck cancer patients themselves – given the lack of qualitative research with this patient group – governed the decision to pursue option three.

There were two key findings from the pilot study which directed the focus of this larger study – the responsiveness of mental images of the cancer, and the importance of other visual concepts embedded in language in understanding treatments. Patients' mental images of the cancer were reported to be stable and enduring, yet they were also

responsive in character, as patients assimilated new information into their original image. This information took the shape of exposure to visual information in the form of pictures or visual language, symptomatic changes, and the perceived impact of treatments. However the retrospective manner in which patients were reporting the development of their beliefs and mental images over time meant that the concept of image evolution was open to criticism, and the credibility of examining this a second time could be considerably enhanced by repeat, time-spaced interviews (Diefenbach, 2009). In view of this, and in light of the apparent importance of mental images and other visual concepts in patients' comprehensions of the impact of different modes of treatment on their cancer, a longitudinal study to further investigate the development of patients' mental images, incorporating an increased focus on images pertaining to treatments, was designed.

In addition to greater trustworthiness when addressing issues of change, other benefits to repeat interviewing have been cited in the literature. Familiarity with the process/researcher may imbue participants with greater confidence, producing more candid, detailed responses to questions (Thomson & Holland, 2003). A deeper rapport between researcher and participant is also facilitated by repeat meetings, and participants are able to reflect upon the subject of interviews during the interim periods (Polkinghorne, 2005). This may enable participants to express their feelings or elaborate on sensitive issues to a greater degree during later interviews (Pattison et al, 2007). Indeed such are the mooted benefits of multiple interviewing in terms of the research relationship and subsequently richer, better-quality data which may be generated, that Polkinghorne (2005, p142) laments:

> "Too often, interview-produced data contain only initial reflections of participants without explorations into the depth and breadth of the experience. In order to obtain interview data of sufficient quality to produce worthwhile findings,

> researchers need to engage with participants in more than a one-shot, one-hour session… most often not sufficient to produce the full and rich descriptions necessary for worthwhile findings."

The participant's account, he argues, is enhanced by virtue of the greater openness and trust fostered through repeated contact with the researcher – the stronger rapport which is so critical to yielding rich data. The latter also benefits from the opportunity to review and interpret transcripts in the intervening periods, and then seek clarification/ expansion from the participant, and thus quality interview data is more likely produced (Polkinghorne, 2005). While this is a logical viewpoint, it is important to note that repeat interviews do not necessarily produce inherently higher quality data. Ultimately, the quality of data generated is governed principally by the quality of the researcher-participant relationship, and this is shaped by the interplay of a range of factors, not merely determined by the number of meetings (Hewitt, 2007; Guillemin & Heggen, 2009). Thomson & Holland (2003), who carried out up to six interviews with young people over a period of 9 years, also point out the challenges of conducting longitudinal qualitative work. Enhanced participant confidence means they are better-equipped to direct the conversation, which may conflict with the intended topic guide, and interviews may also be longer in duration. This results in more lengthy and potentially unwieldy data, in a context where longitudinal analysis is already rather time-expensive (data must be analysed both cross-sectionally and by individual case.

A further difficulty anticipated in undertaking a longitudinal study with patients who are (to varying extents) seriously ill, was that their participation may be compromised by the disease. For example Sherman et al (2005) reported on participant retention while implementing a longitudinal questionnaire study over a 12 month period with a small sample of patients with AIDS/advanced cancer and their caregivers. Eighteen of their 38

advanced cancer patients died before completion of the study, and only five patients completed all of the data collection points. Perhaps surprisingly however, only four of those who withdrew from the study cited being too physically unwell as the reason, with implications for their own psychological well-being – being too 'stressed', or not wanting to be reminded of their illness – more salient barriers to continued participation. On a positive note, the authors also commented on the need of participants to talk about their illness - 'just want to talk' - speculating that a qualitative design may have been a greater draw to continue than completing rigidly defined questionnaires. So while physical debilitation (or death) and psychological self-preservation were predicted obstacles to longitudinal participation, the qualitative nature of this study was also recognised as potentially fulfilling an important patient need, by providing an opportunity for them to discuss their experiences.

The decision to employ a longitudinal design for this larger study was made principally to enable us to examine how patients' beliefs and mental images of the cancer may evolve over time, a perspective which would potentially also further clarify the origins and influences over these. Essentially the focus was to explore patients' beliefs about what was going on inside their bodies, in terms of both the cancer's action and the action of the treatments, over time - with particular reference to mental images and the development of these. Understandings which, as the pilot study findings suggested, may be embedded as much in visual concepts represented in language, as in perceived mental images. The following explicit aim and preliminary research questions were then identified for this study.

8.3 AIM

To explore the role of mental images and visual concepts expressed verbally in head and neck cancer patients' understanding and experiences of their cancer and treatment.

8.3.1 RESEARCH QUESTIONS

1. What are patients' understandings of their illness and its treatment?
2. In what ways and to what extent do patients with head and neck cancer visualise (have mental images of) their illness and treatment?
3. What role do mental images and visual concepts expressed in language play in patients' understandings of illness and treatment?
4. How do patients' understandings/images of what is happening inside their bodies evolve throughout the course of their experience of cancer?
5. What are the perceived origins of patients' mental images?

8.4 DESIGN

A longitudinal qualitative study, comprising 25 head and neck cancer patients participating in semi-structured interviews at two time points – prior to commencing, or in the early stages of, treatment; and approximately one to two months following completion of treatment(s).

8.4.1 SAMPLING

The optimum qualitative approach to sampling is purposive, strategic in the sense that it is a considered, discriminate exercise designed to recruit those participants who can best provide insight into the topic of study. Purposive strategies include maximum variation sampling, in which divergent cases are sought; homogenous sampling, where members of a particular sub-group are recruited; and deviant sampling, where participants are selected by virtue of being 'extreme' cases, to illuminate the parameters of difference (Marshall, 1996; Polkinghorne, 2005). Sampling strategically like this enables the divergence of perspectives and experiences to be explored, minimising selection bias, and therefore enhances the credibility of the research (Barbour, 2001). Ideally a

strategy of maximum variation sampling would have been selected, as the novelty of the topic of mental images meant this is a very preliminary study, and a broadly diverse sample would have enabled us to examine the range of experiences. However, due to practical limitations in terms of the number of new HNC cases available to potentially recruit and the time constraints on recruitment, purposive or selective sampling was not feasible.

Therefore convenience sampling was adopted as the strategy for this study. Essentially this is the indiscriminate selection of participants on the basis of who is available, rather than to achieve breadth and depth of insight into the phenomenon of interest, and it is thereby the least desirable method (Patton, 1990, p180). Convenience or at least accessibility plays a part in all recruitment strategies however, only to a lesser degree, so while the convenient nature of the sampling for this study is a limitation of this project, we would not necessarily concur with Marshall (1996) that this directly raises the likelihood of yielding poor quality data. Convenience sampling meant variation within the sample was out-with our control, though it was anticipated that a natural mix of age, gender, socioeconomic status, disease site/stage, and treatment types – to some degree - would be inherent in the sample. Sample size was based on advice from a relevant HNC specialist regarding the approximate number of new cases presenting each month, though there is a high degree of variability and obviously this was not guaranteed (Taylor, L. 2007. personal communication, 26th November). A target sample of twenty-five patients was set, based on the time available and an optimistic estimate of approximately half of all new patients consenting to take part – an ambitious number.

8.4.2 INCLUSION AND EXCLUSION CRITERIA

Inclusion criteria consisted of patients who had been diagnosed with a head and neck cancer within the past three months. Patients with advanced cancers were not excluded

from the study if they were undergoing palliative treatment and wished to participate. These patients may have unique experiences and understandings of their disease and what is happening inside their bodies by virtue of their poorer prognosis, and therefore merited inclusion. It was recognised however, particularly due to the longitudinal nature of the study, that their participation may be compromised.

As per the pilot study, patients under 18 years old, those who lacked the capacity to provide informed consent, and those who could not speak English sufficiently well to be able to complete verbal interviews were excluded from the study. The clinician making the initial approach to patients was also afforded discretion in determining those whom it would not be appropriate or timely to approach.

8.4.2.1 RECRUITMENT

All eligible newly diagnosed head and neck cancer patients, who were no further than 3 weeks into commencing treatment, were approached by the HNC specialist nurse during a routine contact in the oncology department at Ninewells Hospital. Patients scheduled for surgery as the first part of their treatment were not approached until after the procedure when they were referred on to oncology for further treatment. Patients were provided with an introductory letter and information sheet (see appendices 16, 17 and 4), and invited to consider taking part in the study. Follow-up occurred at the nurse's next routine contact with the patient, be it by telephone, email, or face-to-face. The contact details of those expressing an interest in the study were then passed to the researcher, who contacted each patient by telephone to further discuss the study, seek consent, and if appropriate, schedule an interview.

8.4.2.2 REVISING THE PROTOCOL TO MAXIMISE RECRUITMENT POTENTIAL

Achieving the target sample size was not straightforward. Fifteen weeks into recruitment we had recruited only seven patients, and due to the time constraints on data collection this was concerning. At that point, of the nine patients approached only two had declined. This was an uptake rate of more than two-thirds, which exceeded the hoped for percentage of half of all patients approached taking part. During investigation of the dearth of eligible patients it transpired that in the six months prior to commencing recruitment the department had actually diagnosed an exceptional number of new cases – the full number expected over a twelve-month period. This was unexpected and resulted in an unprecedented shortage of new patients during the recruitment period. This shortage necessitated reconsideration of the planned recruitment strategy, and after some deliberation it was decided to acquire a second recruitment site to maximise the potential for achieving a sample of 25 patients.

The oncology department at Aberdeen Royal Infirmary (A.R.I.) was obtained as a second site via a minor amendment approved by ethics and application to the appropriate R&D (see appendix 21). Approximately two months after identifying the need for another site the same recruitment procedure for new post-surgical patients commenced, implemented by two clinicians in the department. By this time four more patients had been recruited in Dundee, however it was still necessary to relax the constraints regarding the first interview time-point in order to widen the pool of eligible patients. This took the form of approaching all patients who were still undergoing treatment at A.R.I., regardless of how many weeks into it they were. Obviously this was not ideal, but it was practical in the circumstances of restricted time for data collection, and still allowed comparison of data from two time points. Individual differences in stage of trajectory at interview times are explicated in the 'sample characteristics' section of the findings.

8.5 DATA COLLECTION

8.5.1 TIMEFRAME

As interactions with health professionals appeared to be a chief source of patients' beliefs and images in the pilot study, it followed that to detect changes in beliefs it would be preferable to interview them initially very early on in their experiences. The post-diagnosis pre-treatment gap was identified as a window of opportunity for the first interview, though the length of this interval varies between patients. It would have been desirable to interview patients several times in total to truly capture the growth and development of their understandings/mental images, though unfortunately this was not practicable due to time constraints and the necessary wide-spacing of the first and second interviews. Due to the debilitating nature of head and neck cancer treatments (as was outlined earlier in Chapter 2), a mid-treatment interview was deemed to be an unrealistic, as well as perhaps ethically unsound, aim. The second interview was therefore to be scheduled in the post-treatment phase, at least one-two months after treatment completion, in the hope that lingering treatment morbidity would be beginning to subside and patients would therefore be well enough to participate. The lengthiness of patient treatment schedules and inclusion of this post-treatment recovery period into the timeframe, together with the funding and time constraints on this project, was then prohibitive of further follow-up interviews, and so data collection was limited to two interviews per patient, one pre- and one post-treatment.

8.5.2 SEMI-STRUCTURED INTERVIEWS

The purpose of this study was to explore how head and neck cancer patients' understandings of their disease and treatment are both embodied in mental images, and expressed and reflected in visual concepts embedded in language. Semi-structured interviewing was identified as the most appropriate method of data collection, and these

one-to-one interviews were carried out at two time points – the first in the initial stages of treatment, the second beyond completion of treatment. The issues addressed included their beliefs and understanding of cancer and treatments in terms of the five dimensions of Leventhal's illness representations; mental images and other visual concepts conveying literal or figurative images of the disease/treatments; the meaning and importance of these images; and the evolution of such images throughout the course of their experience. Interviews were audio-recorded. During the interview, participants were requested to sketch any mental images of the cancer and treatments, while verbalising the features of these images, as per the pilot study.

In advance of the start of data collection, one-page topic guides consisting of bullet points were constructed to ensure that the pertinent areas of interest were explored in the interviews (see Appendices 18 and 19). As indicated in Chapter 4, the sequence and wording of questions varied as the structure of the interview was directed primarily by the participant. New areas were incorporated into the topic guides as data collection progressed and unanticipated issues were discussed by participants. One example of this was the notion of 'dead cancer'. In the preparatory consideration of mental images and review of the pilot study transcripts, the question of what actually happened to the cancer – when it is conceptualised as a physical, tangible entity – once the treatment had 'killed it off' did not emerge. This was raised spontaneously by the very first two interviewees in this study however, and was therefore noted on the topic guides and addressed in all subsequent interviews.

8.5.2.1 CONDUCT OF INTERVIEWS

The process of interviewing seemed naturally to follow a basic set pattern – informal conversation and rapport-building, refocusing onto the interview, beginning with a narrative account, and then addressing the research questions before closure. Chapter 4

outlined the importance of developing a rapport with participants in order to facilitate disclosure and engagement in the interview. As an initial ice-breaker, some informal conversation with participants upon meeting took place, for example commenting on the location or décor of their home, asking about others who lived in the house, or enquiring after their day. Most participants welcomed this kind of friendly interest, and it helped to create a relaxed atmosphere as researcher and participant shared a little about themselves. The researcher endeavoured to find common interests or experiences about which both could converse, in the form of discussing football with one participant, baking with another, and similarities in family backgrounds. This appeared to help both parties to settle in to the situation, and meant the researcher became familiar with participants' rhythms of speech and mood before the interview itself began. There were a couple of occasions when there was very little of this kind of initial rapport-building conversation, and in these instances the participants tended to take longer to 'open up' in the interviews, a greater initial portion of which was spent establishing trust.

Following the preliminary conversation, the researcher re-orientated the discussion by reiterating the purpose of the study, the nature of the interviews, answering questions, and outlining participants' rights to refuse to answer any question or withdraw from the study at any time without prejudice. At this point consent forms were signed (see Appendices 18 and 19), and the audio recorder produced and set up. The purpose of the topic guide – as a reminder of some of the questions the researcher wanted to ask – was explained, as was the intention to make some notes as the interview progressed, and participants were encouraged to ask questions or take a break from the interview as they wished. The initiation into the actual interview often increased participants' anxiety temporarily, though they appeared to relax relatively quickly.

Oliffe & Mroz (2005) reported using a 'questions, then conversation' approach to interviewing men about illness experiences. Broad, open questions were asked the outset to elicit an initial narrative (chronological) account of their experience, after which specific areas were revisited to address the research questions. The 'questions, then conversations' approach was adopted while interviewing for this study, the researcher seeking clarification of the stage participants were at and the treatments they had scheduled to start off with, then asking them to explain how it all began. Indeed it seemed a very natural manner in which to structure the interviews as participants often began recounting their experience – from symptoms up to the present stage of their illness – spontaneously, in some cases only minutes after meeting and before the audio recorder had been switched on. The overwhelming sense was that the participants were people who wanted to talk about their experiences, and who readily and with very few prompts would 'tell their story'. There were two exceptions to this – a man who as deeply depressed at the time of the interview and struggled to articulate himself, and a woman who was extremely reticent in talking about her cancer, who was also somewhat in a state of shock at the diagnosis, and who strived to think about it as little as possible – and these interviews were accordingly very limited in terms of expansion on points raised, with heavier input from the researcher.

Participants' chronological accounts provided the basis for a deeper exploration of the issues of interest. With reference to the topic guide the researcher sought clarification of meaning and used spontaneously stated beliefs as a launch-pad to elicit a range of views on the nature of their cancer and treatments, and how participants understood these. Attention was paid to the presence of visual concepts embedded in language in the telling of their stories, and specific references were revisited during the latter part of the interview. In the majority of interviews, the notion of a mental image of the cancer was also addressed in the later stages. This was done purposely with the aim of first

scrutinising patients' descriptions of the cancer where images were not the explicit focus to see if visual language was inherent to these, which would perhaps indicate greater salience of the mental image. As interviews drew to a close, participants were asked if there was anything they would like to add, and encouraged to raise any questions or concerns. The support services booklet (see appendices 8 and 9) was given out, with a brief spiel outlining the kinds of support offered by the organisations, and participants were also reminded of the clinical support available to them. The researcher then explained she would contact participants one-two months after they had completed treatment to arrange the follow-up interview, reiterating their right to withdraw from the study or contact the researcher at any time should they have any queries, and thanked the participant for their time.

8.5.2.2 ACCESSING INTERNAL MENTAL IMAGES

The design of the main study was expanded to include greater attention to patients' use of visual concepts in language, and while mental image re-creation remained an important part of the data collection, based on the utilisation of materials in the pilot, it was deemed reasonable to condense the toolkit. There was a practical element to this decision also, as the researcher was a non-driver and travelling widely to patients' homes had required transporting a bulky and fairly heavy additional case containing the materials on public transport. Simple materials were favoured by the pilot participants to make a basic re-creation of their image by drawing – plain paper and a few carefully considered coloured pens and pencils. A few of the participants chose plasticine to represent the size of the tumour and the characteristics of consistency and texture, while only one patient used any of textural materials provided such as beads and cork. An important aspect of the discussion about the re-created image was how accurately participants felt it represented their internal mental image, and little reticence was exhibited in articulating the inadequacies in what was produced. Therefore the provision

of only basic components of the toolkit for image re-creation in the main study - plain white paper and an assortment of coloured pens and pencils – was considered not necessarily detrimental to patients' ability to describe their mental images in detail, though obviously it would limit the type of re-creations produced.

8.6 ANALYSING THE DATA: INTERPRETIVE PHENOMENOLOGICAL ANALYSIS (IPA)

IPA is both a holistic qualitative research philosophy and an approach to data analysis, originating from the field of health psychology. It is phenomenological in the sense that it is concerned with understanding the subjective, rather than objective, meanings and perceptions of experience. The interpretive of the title refers to the interpretation of the researcher in trying to gain insight into the other's perspective, something which is determined and complicated by one's own conceptions, and therefore cannot be achieved in any complete sense (Reid, Flowers, & Larkin, 2005). The core principles of IPA then – the emphasis on the subjectivity of experience and data generation, the role of the researcher, and need for interpretation to understand experiences – are congruent with the constructivist stance underpinning this project, and its purpose in line with the topical focus on the experiences and meaning of imagery in the context of head and neck cancer.

IPA is an inductive, exploratory approach to data analysis, and while this project was novel and exploratory in terms of the focus on imagery, as mentioned earlier it also involved the elicitation and analysis of illness beliefs which were preliminarily defined in accordance with the five dimensions of Leventhal's illness representations. The adoption of IPA was therefore atypical in this respect (Brocki & Wearden, 2006). However its application in qualitative studies which are not wholly exploratory in nature and include

some examination of existing theoretical constructs is not unprecedented (Carradice et al, 2002; Harman & Clare, 2006), and as a perspective on data analysis which was consistent with our prevailing approach to the project we felt IPA remained a valid selection to guide analysis.

8.6.1 THE IPA PROCESS

There is no definitive, rigid formula one must follow to analyse data from an IPA approach (Brocki & Wearden, 2006), though procedural guidelines have been advanced with the intention that they serve as a starting point for researchers to implement as desired. The procedure for analysing the data in this case was based on Smith, Jarman, & Osborn's (1999) template, which broadly speaking involves 6 stages:

- Stage 1: Initial coding – The first transcript is carefully read until familiar with the text. Initial impressions, significant statements, and early interpretations are noted; and preliminary codes or themes assigned.
- Stage 2: Making connections – A separate list of these preliminary themes is constructed during the initial coding, and this is examined to identify the connections or relationships between the themes.
- Stage 3: Constructing a master list of themes – The list of themes is refined into a comprehensive master list which is structured in a coherent manner.
- Stage 4: Analysing further transcripts – Stages one to two are repeated for each subsequent transcript, with the master list of themes (created during stage 3) forming the basis for the interpretation and newly emerging themes being incorporated into this list.
- Stage 5: Intensive analysis of individual themes – The individual themes within the coding framework (the master list of themes) are examined to determine the appropriateness of the coding and to identify sub- and super-ordinate themes.

- Stage 6: Investigating patterns, connections and tensions – The body of themes is scrutinised to identify related or conflicted codes and patterns in the coding of the data.

This method is presented in stage-by-stage fashion here for purposes of clarity, but it should be noted that the process is not in fact linear in style, but cyclical – and required constant: referral back to the original data, revision as to the appropriateness of theme labels, and searching for new themes amongst the earlier transcripts. Audio recordings of the interviews were transcribed verbatim by an external transcription company (the researcher transcribed five of the interviews); and the field notes created during and shortly after the interviews were also referred to during the analysis to assist the interpretation of the transcripts. In accordance with the six-stage template set out above (Smith, Jarman, & Osborn, 1999), the process of analysis could be divided broadly into two phases - the coding of all the individual transcripts (stages 1 to 4), followed by the investigation of the collective data (stages 5 to 6). and the remainder of this chapter will outline the development of the analysis in more detail.

8.6.1.1 CODING OF INDIVIDUAL TRANSCRIPTS

The first two stages of the analysis were carried out more or less in tandem using a printed copy of the text. Following the careful reading of and familiarisation with the transcript, initial impressions, points of significance, and early interpretations were then noted down in the left-hand margin, and preliminary codes or themes noted in the opposing margin. This initial coding was largely descriptive and referred mainly to the content of the text. Concurrent to this a separate list of the emergent themes was constructed, and this list facilitated reflection on the connections between codes – whether they supported or contradicted each other, or there were clusters which should be drawn together under a parent theme. This document provided the basis for the

preliminary coding of the transcript in Nvivo – a software program which facilitates the storage, coding and cross-referencing of qualitative data – and it was during this process that the preliminary themes were revised to reflect the connections identified. The final part of the individual analysis of the transcript (stage three) was to type up and refine the list of themes into a comprehensive 'master list' which was structured in a more coherent manner – the themes organised hierarchically and alphabetically (see Appendix 22). This master list of themes was then duplicated for use when coding further transcripts (stage four) while preserving the original. Newly identified codes were incorporated into subsequent lists, and their identification was tracked by the use of different font colours.

8.6.1.2 INVESTIGATING THE COLLECTIVE DATA

The coding framework evolved throughout the process of analysis as new themes emerged and preliminary categories were reconsidered in light of these. The most intensive analysis of the coding was carried out following completion of the set of individual transcripts from each round of interviews however (stage five). The aim of this phase of the analysis is to further refine and improve the coding framework, identify cross-category codes, and to establish the appropriateness of theme labels. The Nvivo program enabled all of the data coded to a specific theme from the entire body of transcripts to be collated in one place, whilst preserving the original transcripts intact, and this facilitated the scrutiny of the nature and components of individual themes and consideration of the richness of the supportive excerpts from the data. The definitive master list of themes was also employed at this stage to inform the further refinement of themes to ensure the coding framework adequately and meaningfully expressed the variation and range of perspectives within the data.

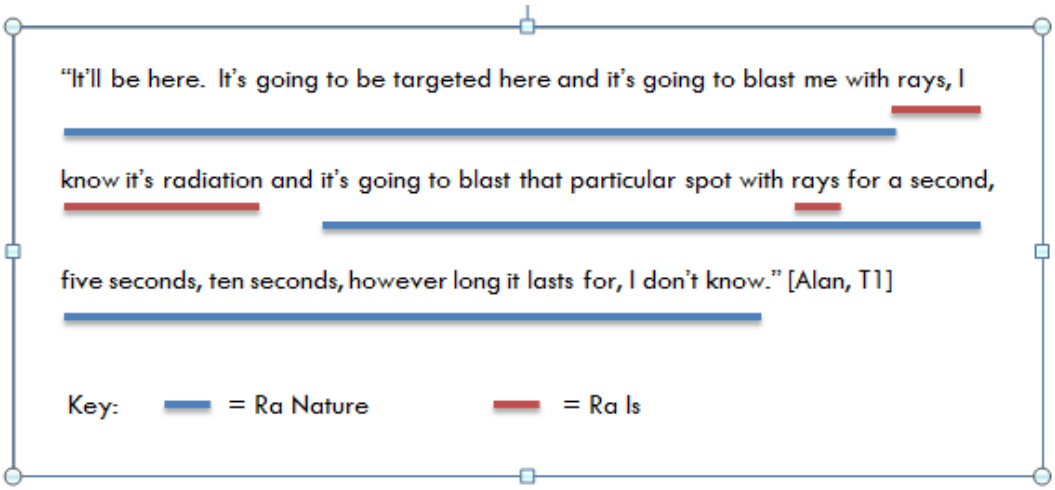
It is important to point out here that not all of the individual themes were subject to the kind of intensive analysis. As shown in the example master list of themes (Appendix 22), the topics covered in the interviews were wide-ranging, and considerable data pertained to the broader aspects of patients' experiences of having cancer – for example their coping strategies, the impact of their diagnosis on their partner or children, the lifestyle changes imposed by the side effects of treatment. The sheer volume of data made intensive investigation of all of these themes impractical, and so it was necessary to be selective about which areas of the data to examine more closely. This selection was therefore guided by the specific research questions the study sought to address (listed on p258 of this chapter), from which three general topic areas were designated as warranting detailed analysis:

1. Beliefs and feelings about cancer and treatments
2. Mental images of the cancer and/or treatments
3. Potential sources of these beliefs (e.g. information from health professionals)

8.6.1.2.1 ANALYSIS AND REFINEMENT OF INDIVIDUAL THEMES - UNDERSTANDING RADIOTHERAPY

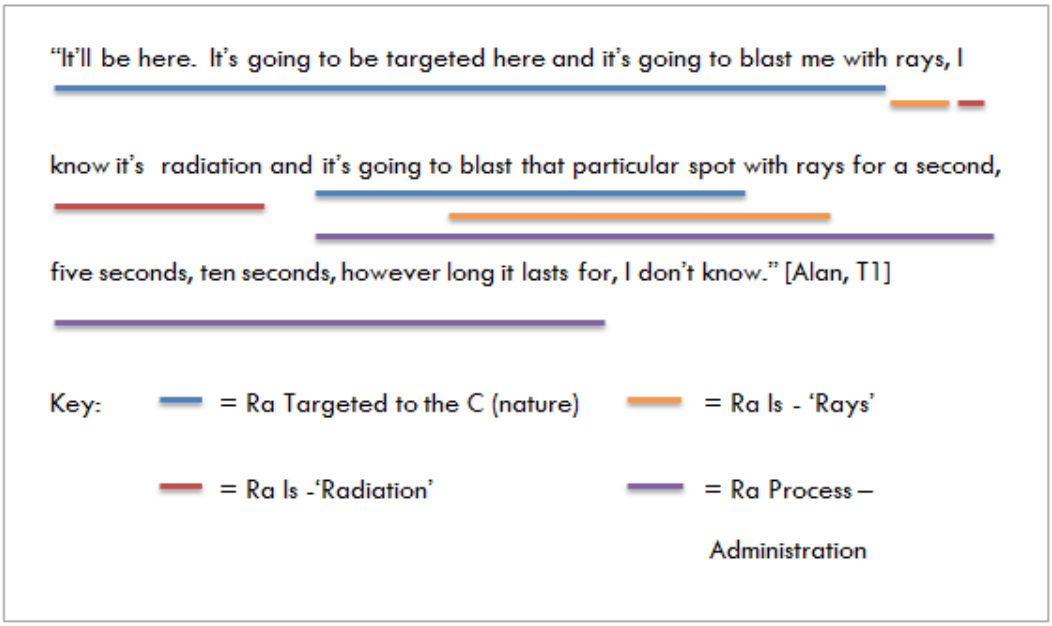
One of the aims of this study was to explore how patients understood the different treatments they were undertaking, such as radiotherapy. Initially data pertaining to the understanding of radiotherapy was coded to broad categories which referred to the content of the data but did not characterise it. For example the excerpt shown in Box 2 was coded to two broad themes denoting beliefs concerning what radiotherapy is – 'Ra Is…' and 'Ra Nature'.

Box 2 **– Initial coding**



Breaking down the data into categories in this manner during the coding of the individual transcripts provided a structure for considering the different aspects of patients' beliefs about radiotherapy. At the penultimate stage of the analysis process these individual codes were then subject to more intensive analysis, the data coded at each theme reconsidered to derive more meaningful themes which captured the content or features of these categories, until it was felt the coding framework adequately reflected the range of components of patients' understandings of radiotherapy. The coding of the same excerpt during this phase is illustrated in Box 3 below.

Box 3 **– Detailed coding**



As shown in this example, this more intensive analysis produced codes which more meaningfully characterised the data. While individual themes were reconsidered, the master list of themes was revised to reflect changes in the coding framework (ensuring each new code was accounted for), and more clearly detail the components of each theme as derived from all of the supporting data. Table 18 below illustrates the development of part of the coding framework for radiotherapy beliefs in this manner in relation to the question what is radiotherapy?

Table 18 – Excerpt of radiotherapy coding framework

Category of beliefs	**The Identity of Radiotherapy**	
Sub-categories	**Radiotherapy Is… (Label)**	**Nature of Radiotherapy (Features)**
Component themes (range of beliefs)	Radiation	Targeted
	Rays or x-rays	Invisible
	Laser	Indiscriminating
	Beams	Painless
	Radiowaves	Dangerous

8.6.1.2.2 EXPLORING PATTERNS IN THE DATA

The final phase of the analysis (stage six) was to examine the data for relationships and conflicts within the body of themes and between and within particular participants. The explication of the nature and components of individual themes during the previous phase (stage five) was a necessary precursor to the identification of patterns in the coding framework. The aim of this final phase of analysis is to clarify differences and similarities in the coded data and how such patterns might be explained. This was a continual process of alternating between examination of specific sub-parts of the thematic coding and consideration of the body of themes as a whole, and involved studying the overlapping, clustering and congruence of themes as well as the characteristics of the

participants. In simple terms identifying patterns is about asking questions of the coding of the data. Typical kinds of questions to be applied to the data would include for example:

- Are participants' viewpoints diametrically opposed or do they exist on a continuum?
- Could demographic characteristics or differences in reported experiences explain divergences in perspectives?

More specific questions may arise from the data itself due perceptible relationships between different themes, through the application of relevant theory, or may be somewhat pre-determined depending on the research questions. The primary aim of this study was to characterise patients' beliefs about and mental images of their cancer and treatments and to explore how these may be related, and so some questions were immediately pertinent – for example are particular dimensions of illness representations such as beliefs about cause or consequences reflected more saliently in patients' mental images of their cancer? In order to 'answer' these questions it was necessary to draw distinctions in the data by identifying patterns in the coding. In practical terms the identification of patterns involved simple procedures of counting and comparing themes. A fuller explanation of how this was carried out is provided in the subsequent chapter where apparent patterns in patient features and the characterisation of cancer as either a 'destroyer' or a 'life force' are outlined.

8.6.1.3 OVERVIEW OF THE PROCESS OF ANALYSIS – A WORKED EXAMPLE

This example uses the 'cancer as destroyer' theme to illustrate the development of the coding from simple descriptive categories to the identification of a core concept.

8.6.1.3.1 EXCERPTS OF DATA

"So er, that was my understanding of the, the cells. You know they're, they grow, they start, they grow, they're eating away at flesh or whatever they're, they're in contact with." [Steve, T1]

"It's the body turning against me. The DNA's been corrupted and it's slowly poisoning me and creating tumours and eventually well, it'll do its job and that'll be it." [Norman, T1]

"Maybe there's a weak part of the body and somehow or other it gets attacked by this cancer, whatever they've got. It is … [like it says] 'let's go for that!' you know, before we know where we are we've got this horrible cancer." [William, T1]

"It has to latch on to something and then they [the cancer cells] start breaking down. They need a host, don't they? So, they latch onto that and they start, basically, making base camp and setting out their nasty stall and they end up taking over from there." [Christopher, T1]

"I think they [the cancer cells] actually highjack your body don't they, they actually get a better blood supply in, a bit of nutrition and all of that and the normal tissue [is damaged due to this], that's why they're able to grow so fast." [Christopher, T2]

8.6.1.3.2 SIMPLE CODING

The preliminary descriptive coding of these excerpts generated a range of themes, including for example:

- C is like a poison
- C 'attacks' the body

- C seeks out weaknesses in own body
- C is 'eating away'
- Cancer 'hijacks' your body
- C 'takes over' tissues

8.6.1.3.3 EXPLORATION OF THEMES, REFINEMENT AND INTEGRATION

As the analysis progressed, individual themes were studied with reference to the entire coding (the master list of themes), and by referring back to the original data. This enabled the merging of similar themes and the identification of overarching categories. For example "c 'attacks' the body", "c is 'eating away'", and "c 'takes over' tissues" represented behavioural imagery of the cancer, and were (along with numerous other themes) organised hierarchically into this category. Meanwhile "c is like a poison", "cancer 'hijacks' your body", and "c seeks out weaknesses in own body" were subsumed into a set of themes which referred to participants' beliefs about the identity and nature of cancer as a disease.

8.6.1.3.4 IDENTIFICATION OF CORE CONCEPT: CANCER AS DESTROYER

Consideration of the refined coding eventually generated the unifying theme of 'cancer as destroyer'. This concept was developed from numerous themes – significantly more than are presented here – which encompassed several aspects of patients' visual and non-visual knowledge of their cancer. It was one of the key themes from the longitudinal study, and represents the characterisation of the cancer as 9 patients' understood it, in contrast to an alternative 'life force' characterisation. Inherently visual in nature, 'cancer as destroyer' chiefly represented the perceived behaviour (and therefore consequences) of the cancer within the body.

8.6.1.4 CODING A LONGITUDINAL DATASET

The dataset for this longitudinal study consisted of two sets of patient interviews – one round of pre-/early- treatment interviews (T1 interviews), and a follow-up round of post-treatment (T2) interviews. It was necessary to analyse the data both longitudinally and cross-sectionally, looking at an individual's experiences over time, as well as examining the entire set of pre-treatment, and then post-treatment, interviews. The preliminary analysis of the T1 interviews was highly individualised, considering each participant as a single case, as the primary purpose of this was to inform the patient's second interview by explication of the beliefs, understandings, relevant imagery, and pertinent aspects of the experience peculiar to each case. A summary document of the salient points was then prepared and referred to by the researcher during the follow-up interviews (see Appendix 23). That is not to say that the preliminary analysis was entirely case-by-case however. Emerging themes accumulated as the analysis progressed, and previously-coded transcripts were interrogated for evidence of these new themes.

The coding of the time-one (T1) transcripts was informed by the concept of illness representations which underpinned the thesis. That is not to suggest that the analysis was confined to the terms of this theory, but rather that in trying to explicate how the patient made sense of their cancer – to identify their illness beliefs – the dimensions of identity, cause, consequences, timeline, and cure/control put forward by Leventhal were used to organise the data in the first instance. However discussion of the initial findings from T1 interviews revealed that the application of this concept appeared to be imposing too much on the interpretation of the data. Intended to be applied as an initial framework for organising patients' beliefs, it became apparent that the dimension labels were not usefully reflecting the content of themes, and that in fact a purely inductive approach to labelling would be more appropriate, and facilitate more meaningful development of conceptual categories. Thus the master list of themes was not employed for the second

round of data analysis, and the researcher began anew with a blank list of themes, deriving more meaningful thematic labels from the data. These more inductive codes were then compared and merged as appropriate with the codes employed during the first round of analysis to produce a definitive coding framework which ensured all of the data was coded consistently.

8.7 CHAPTER SUMMARY

This chapter has outlined and justified the design of the final empirical phase of this project, a longitudinal qualitative study exploring the role of mental images and visual concepts embedded in language in patients' understandings and experiences of head and neck cancer and treatment. The potential advantages and difficulties in implementing a longitudinal design with this patient population have been discussed, and the convenience sampling strategy and incorporation of a second recruitment site to achieve the target sample have been detailed. Derived from the findings of the pilot study (phase one), this study employed substantially the same methodological approach. Data collection was via semi-structured qualitative interviews, and image re-creation was facilitated using a pared down version of the toolkit trialled in the pilot. The data from this study was analysed according to the principles of interpretive phenomenological analysis both cross-sectionally and longitudinally, using Nvivo software to organise and cross-reference the copious amounts of data. The demographic and disease characteristics of the study participants and the findings from this study are conveyed in the following chapter. The final chapter of the thesis will then demonstrate how these findings relate to those of the pilot study, and the meta-synthesis in particular. It will attempt to integrate the findings of all three research phases, and will present some theoretical and methodological conclusions, as well as a discussion of the implications for future research and clinical practice.

9 THE LONGITUDINAL STUDY – FINDINGS

9.1 INTRODUCTION

The previous chapter described the rationale, design and methodological approach to this study, the aim of which was to further explore the ways in which HNC patients understand and visualise their disease and treatments, and how this may evolve over the course of their experience. The findings presented here illustrate the role of mental images in the broader understanding and experiences of cancer and treatment. This chapter presents an essentially descriptive analysis of the findings in relation to the existence, origins and meaning of mental images. It also relays findings which raise questions about the original thesis' focus on explicit mental images of the cancer – that is images which are acknowledged by the patient as existing in their mind's eye. The findings of this study suggest that mental images may also be implicit in nature, and that though not acknowledged by the patient such underlying images are indicated by their use of vivid visual language which conveys an image of the cancer which may be envisaged in the mind's eye. The prominence of other visual concepts embedded in language in relation to treatments is also described. A more conceptual analysis and assessment – including consideration of this implicit/ explicit interpretation of the findings – along with potential theoretical, methodological and clinical implications is then provided in the subsequent discussion chapter.

Analysis of the data revealed the importance of mental images to lie in their facility as an explanatory tool within patients' own minds – both reflecting their beliefs and appearing to 'fill in the gaps' in their understanding of what is going on inside their bodies. Cancer itself and the treatments constituted 'uncharted territories' for these patients, and visual knowledge – that is knowledge, understanding or beliefs embedded in explicit or implicit, realistic or figurative, images of the cancer and treatments –

represented one facet of the mind's attempts to make sense of these. Data collection generated a wealth of data pertaining to the experience of head and neck cancer more generally, and how it impacted on the lives of individuals – Appendix 22 (one of the 'master lists' of themes) illustrates the broad scope of the study data in this respect. The majority of this is not reported on here due to size considerations and the desire to first present the image-related findings which was the primary remit of this exploratory project, however it is hoped that this ancillary analysis will be published elsewhere.

Following an overview of the demographic and disease characteristics of the sample, the findings consist of four parts. Firstly, the range of mental images of the cancer will be described, and a distinction will be drawn between these reported images in terms of being explicit or implicit in nature. Differentiation between two kinds of mental image – the characterisation of the cancer and its behaviour as either a 'destroyer' or a 'life force' – will be outlined, and the perceived origins of patients' images of the cancer will be delineated. Part two will outline how patients conceptualise cancer as a disease, and how mental images reflect specific beliefs about their illness. Their comprehension of various treatments embodied in visual concepts embedded in language – and the distinction of these from mental images – will then be explored in a third section. The final part of this chapter is devoted to the issue of how patients' mental images of their disease and what is going on inside their bodies evolves over time. The form and function of mental images in these respects will be embedded within each section, as it was impossible to extricate visually-based beliefs (visual knowledge) from non-visually based ones.

9.1.1 SAMPLE CHARACTERISTICS

The sample comprised 25 head and neck cancer patients, and 19 of these completed both interviews. Two-thirds of the sample (n=17) was recruited from the original site in

Tayside, the final third from the second site in Grampian. The ages of participants at primary interview ranged from 31-79 years old, and the ratio of male to female participants was approximately 2:1. Details of each patient's participation in the study, plus age and gender characteristics are outlined in Table 19.

Table 19 - Age, gender, level of participation, and interval between primary and follow-up interviews

No.	Participant	Gender	Age	Participation Level	Interview Interval
1	Steve	Male	52	Full – Both Interviews	6.5 months
2	Andrew	Male	43	Full – Both Interviews	8 months
3	Nell	Female	71	Full – Both Interviews	9.5 months
4	Alasdair	Male	54	Full – Both Interviews	8.5 months
5	Eric	Male	70	Full – Both Interviews	9 months
6	Gary	Male	50	Primary Interview	N/A – died
7	Olive	Female	76	Full – Both Interviews	3 months
8	Scott	Male	48	Full – Both Interviews	6.5 months
9	William	Male	69	Primary Interview	N/A – withdrew
10	Barry	Male	69	Full – Both Interviews	5 months
11	Norman	Male	55	Primary Interview	N/A – died
12	Katrina	Female	41	Full – Both Interviews	7 months
13	Cathy	Female	48	Full – Both Interviews	6 months
14	Ashley	Female	46	Full – Both Interviews	6 months
15	Alison	Female	72	Primary Interview	N/A – withdrew
16	Lewis	Male	71	Full – Both Interviews	5 months
17	Frederick	Male	65	Primary Interview	N/A – died
18	Lesley	Female	56	Full – Both Interviews	6 months
19	Jean-Claude	Male	31	Full – Both Interviews	5 months

20	Christopher	Male	56	Full – Both Interviews	5 months
21	Kirk	Male	65	Primary Interview	N/A – withdrew
22	Brian	Male	52	Full – Both Interviews	6.5 months
23	Alan	Male	37	Full – Both Interviews	5.5 months
24	Albert	Male	79	Full – Both Interviews	4 months
25	Jill	Female	60	Full – Both Interviews	4 months

An incomplete dataset was anticipated due to the longitudinal nature of the study, the fact that the target sample are suffering from a serious illness, and the inclusion of patients with terminal prognoses, and this was the case for six participants. Three patients died during the course of their treatment (only one of whom had an incurable prognosis at primary interview) and three patients withdrew from the study, equating to a full participation level of approximately three-quarters of the sample. Of those who withdrew, one did so as his cancer had recurred during the interim period and his prognosis was consequently very poor. The reasons for the other two patients' withdrawal were unclear however. One did not give a reason (as was her prerogative under the ethical guidelines), whilst the other repeatedly stated their wish to participate in the follow-up interview, yet continually postponed setting a date for the appointment, requesting to be 'called back'. This appeared to signify an unspoken wish to withdraw from the study in spite of verbal assurances to the contrary – an issue which has been noted by others, i.e. Sherman et al (2005) – and while this was unconfirmed, eventually the time restrictions on data collection ruled this patient out of follow-up.

9.1.1.1 DEPRIVATION PROFILE OF THE SAMPLE

A measure of the socio-economic status of participants was not incorporated into the pilot study, however for this larger study participants were scored according to their postcodes on the 'Scottish Index of Multiple Deprivation (2006)' (SIMD) to allow further

delineation of the sample characteristics. The SIMD combines a range of data, including details of income, education, employment and crime, to produce a relative ranking of each area from most to least deprived (www.sns.gov.uk, 2006). These scores are indicated in the table 20 below.

Table 20 **– Deprivation Profile of Sample**

SIMD Decile 2006	**Per Decile**		**Per Fifth of Ranking**	
	No. Patients	**% of sample**	**No. Patients**	**% of sample**
1 – most deprived	5	20%	6	24%
2	1	4%		
3	2	8%	3	12%
4	1	4%		
5	2	8%	4	16%
6	2	8%		
7	4	16%	7	28%
8	3	12%		
9	3	12%	5	20%
10 – least deprived	2	8%		
	25	100%	25	100%

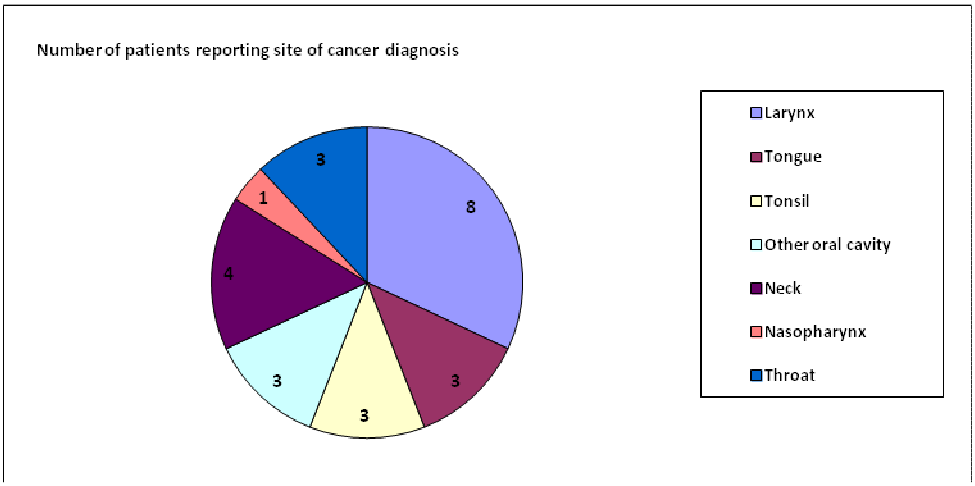
As this table shows there was a predominance of more affluent patients within the sample – fourteen of the twenty-five participants from the upper five deciles. However the distribution of patients across each decile also affirms that the sampling strategy succeeded in recruiting participants from a range of social backgrounds, despite being convenience-based rather than purposive in nature.

9.1.2 CANCER SITES AND TREATMENT REGIMENS

Laryngeal cancer was the most common type amongst the sample, comprising eight patients. Seven further patients described their cancer as located in their 'throat' or 'neck', two of whom stipulated that the precise location of their cancer was unconfirmed, only detected in this area. Cancer of the oropharyngeal cavity was diagnosed in nine

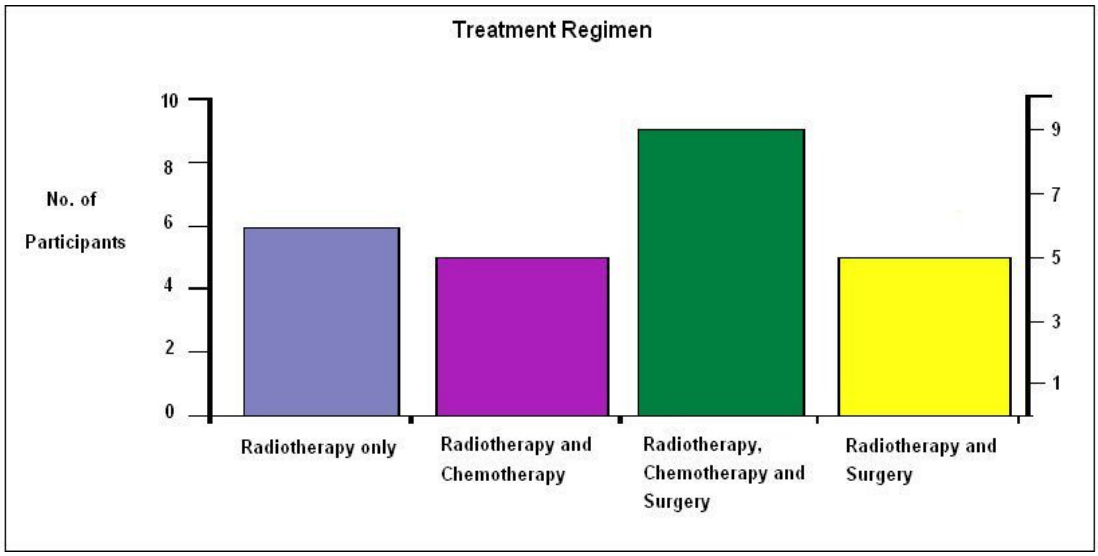
patients: three of the tongue, three of the tonsils, and three of other oral tissues. There was also one case of nasopharyngeal cancer. Figure 9 below shows the primary site of the participants' cancers proportionately.

Figure 9 - Disease profile of the sample by site



Patients in this sample underwent one of four treatment regimens. All participants were treated with radiotherapy – five in addition to surgery, and five in conjunction with chemotherapy. Two of the combined chemo- and radio- therapy patients were being treated palliatively from the outset. Nine patients had all three modes of treatment. Of the fourteen surgical patients, twelve had their cancer, or at least part of the cancer, excised. Six of these also underwent a unilateral neck dissection – removal of tissues including muscle, fat, lymph nodes, and nerves from the affected side of the neck. The final two surgical patients were initially treated with radiotherapy and chemotherapy, and had unilateral neck dissections as the final stage of their treatment.

Figure 10 - Variance in treatment regimens



9.2 PART ONE: IMAGES AND ORIGINS

Part one of the findings will detail the range of images of the cancer reported by participants, and recount the apparent origins of these. The chapter will begin with a commentary on the dearth of image drawings produced by patients in this sample, and will introduce the notion that mental images may be implicit as well as explicit in nature. It will be suggested that mental images may exist on a more tacit level, and that the existence of underlying implicit mental images of the cancer is suggested by data from a number of patients who did not acknowledge an image of the cancer but went on to talk about the physical form of the cancer in a way which could be envisaged in the mind's eye. A full index of patients' mental images – in pictorial and textual form – is then provided. The different types of images will then be described according to their level of sophistication, and realistic/literal or figurative nature. Two themes concerning the characterisation of the cancer were discerned, a destructive orientation ('cancer as destroyer'), and a non-destructive orientation ('cancer the life force'). These concepts appeared to be linked to differences in age, anxiety, and social engagement; and these

findings will be presented subsequently. The final section of this part will then describe the origins of these mental images so far as they have been identified.

9.2.1 CREATIVE RETICENCE – A LACK OF IMAGE RE-CREATION

Despite the fact that almost all patients verbally relayed some kind of image of their cancer, the presentation of these images is hindered by a prevalent reluctance to re-create these images amongst the sample – a reluctance which was not shared by the participants in the pilot study. Only eight patients attempted to draw their cancer, and only two of these drew an image at both interview time-point 1 (T1) and interview time-point 2 (T2). The widespread inhibition to re-create images appeared to be attributable to patients either not regarding their verbally expressed image of the cancer as a mental image – due to either the subjective nature of deciding what an 'image' of the cancer is, or because it was an implicit image; or having an explicit (acknowledged) mental image but feeling unable to re-create the image on paper, or simply not wanting to do so.

The patients in this study made extensive use of visual language with reference to their cancer and treatments throughout the interviews. In fact the majority of what is termed 'visual knowledge' in this thesis was revealed through conversation in this way, as it had been with the participants in the pilot study. Despite this, numerous patients stated that they had 'no idea' what the cancer was, or had 'no image of it' at all, whilst having previously or subsequently provided a vivid verbal description of the cancer!

> Researcher: "Do you have any thoughts about what your cancer actually looks like?"
>
> Katrina: "No."
>
> Researcher: "… And what the tumour looks like?"

Katrina: "I just thought it was a round … something round and fleshy"

[Katrina, T1]

Researcher: "Did you ever have sort of an image of your cancer like that at all?"

Albert: "No, no. I just thought it was a… a very small growth that was there, and how it got there I don't know." [Albert, T1]

This apparent incongruence in some patients' accounts, where they talked about the cancer in a manner which suggested an underlying mental image of it but answered negatively to direct questions about whether they had such an image, raised two issues not previously considered when designing this study – the potential ambiguity of the notion of an 'image of the cancer', and the issue of awareness of internal images.

9.2.1.1 WHAT CONSTITUTES AN 'IMAGE' OF THE CANCER

Though almost all patients articulated an impression of the physical form of the cancer which may be envisaged in the mind's eye several did not consider this to constitute a 'mental image' of it, and therefore the question of re-creation appeared non-applicable to them. Because this had not been the case during the pilot study, mid-way through data collection it was decided to investigate how the topic was being broached by the researcher, in case any distinctions in terminology could explain this. Comparison of the phrasing used during the pilot and main studies revealed very little difference however, the researcher again using words like 'have you ever thought about/had ideas about/imagined what your cancer looked like?' for example. Also as per the pilot, the terms patients used to describe the cancer were reflected back to them when asking further about mental images.

However a possible explanation may lie in the type of images related by some of these patients. A number described the cancer primarily in terms of its anatomical location, and while they had a conception of its size or configuration in relation to other parts of their body because they could not "picture" what the cancer itself looked like, they did not consider their image to constitute an image of the cancer. Examples in this respect include Andrew – who could visualise the location of his cancer but not the cancer cells, and Olive – in whose image the location of the growth between the vocal cords was key, but the growth itself lacked definition. There were no set parameters which an image must reflect in order to be considered an image of the cancer for this study, and so these cases are still considered to be 'mental images' of the cancer. Although not self-defined strictly in the terms of a "mental image", these patients conceptualised their images to represent how they 'pictured', 'imagined', or 'visualised' their cancer, and therefore these images are regarded as explicit (acknowledged) mental images perceived in the mind's eye.

9.2.1.2 THE CASE FOR IMPLICIT IMAGES

Despite the extensive consideration given to methods and potential issues in communicating mental images (as reported in Chapter 3), this omitted the necessity of awareness of an image as a precursor to communicating it. An assumption had been made at the outset that if patients did indeed have a mental image of their cancer that this would be readily accessible to them and therefore communicable via language or pictorial representation. However the data from this study suggested that in fact patients' mental images of the cancer may exist on a continuum – being more implicit or more explicit in nature – and so the issue of whether patients had a mental image of their cancer was rather more complex. Approximately one-third of the patients in this study related what are considered to be implicit images of the cancer. That is they articulated a visual knowledge of the cancer – reporting some beliefs or aspects of their

understanding which appeared to be embedded in an underlying image of the cancer – but did not report this as a mental image. To be considered an implicit image the form of the cancer had to be referred to in a consistent fashion throughout the interview.

It is accepted that this is only possible interpretation of this data, for example it could be argued that participants' use of visual language in talking about their cancer reflected only the utility of verbal images in expressing thoughts and beliefs about cancer, but that these thoughts and beliefs were not necessarily tied to or indicative of an underlying visual mental image. That is not the contention here however, and the findings of this study will be presented in accordance with the interpretation of the data as indicative of an implicit-explicit continuum upon which mental images may exist.

9.2.1.3 OTHER REASONS FOR DECLINING TO RE-CREATE AN IMAGE

Amongst those who did consider their visual descriptions of the cancer to constitute an image of it (those who held explicit mental images), the most-cited reason for declining to draw it was feeling unable to do so with any accuracy. In a number of cases this was because they were embarrassed about their artistic abilities, despite assurances that it was not an art test, and that the purpose of re-creation was simply to enable the researcher to have a better understanding of how they envisioned the cancer.

> "You see, I don't think I'd be capable of drawing it. It would just be a couple of squiggles to be honest. But that would be my explanation of how my personal, how I perceive it to be." [Christopher, T1]

> "But no, in terms of visualising-, as I say I couldn't show you, I couldn't draw a picture of a healthy tissue, so I couldn't draw a cancerous one or whatever." [Andrew, T2]

Finally, a small number of patients refused to re-create their cancer without giving a reason. In one case it was evident via the participant's change in tone and body language when responding to the question that she found the notion of drawing the cancer distressing, and this was respected. In other cases it was more difficult to read the underlying reason, Lesley for example stating boldly, and with a mocking laugh:

> "I hate drawing. You do the drawing!" [Lesley, T2]

9.2.2 INDEX OF PARTICIPANTS' MENTAL IMAGES OF THEIR CANCER

The dearth of patient drawings means it is harder to convey the range of ways in which participants envisaged their cancer. Table 21 below indexes all ten drawings produced by the eight participants who did re-create their mental images. The subsequent table summarises – largely in participants' own words – both those images of the cancer described by patients who also acknowledged a mental image of the cancer (explicit image), but declined to re-create it either because they did not consider it to constitute an 'image of the cancer', or because they simply did not wish to; and those which appeared to be implicit images of the cancer described verbally by participants. Together these tables help to demonstrate the huge variation in images amongst this sample, and the subsequent section goes on to delineate the range of different types of images proffered by participants.

Table 21 – Index of all images re-created by participants. NB – Not all described characteristics are represented in these drawings.

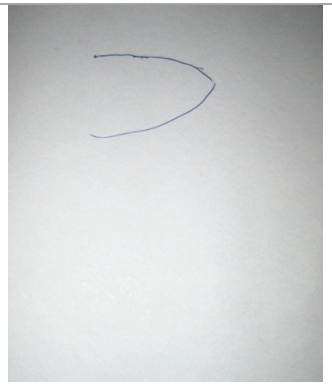
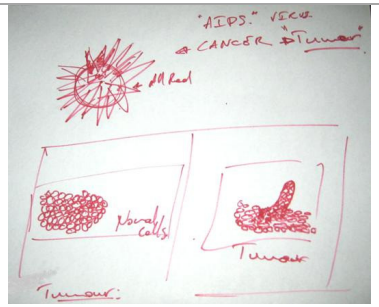
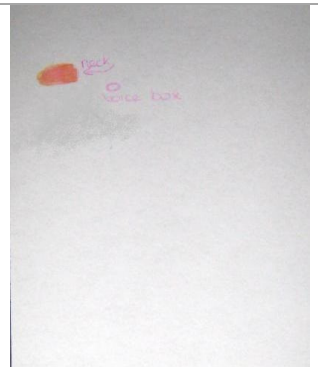
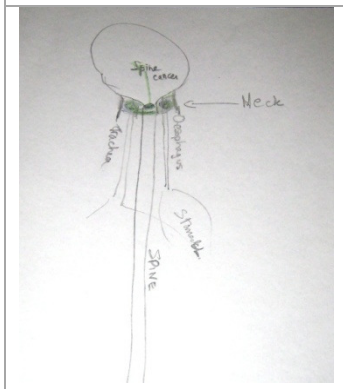
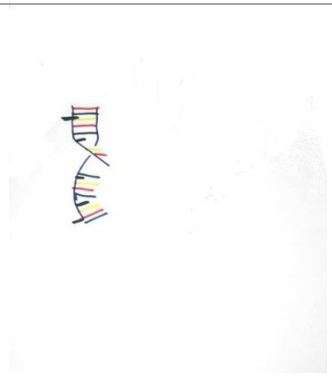
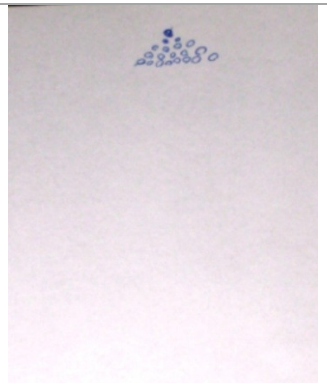
#1 Alan – 37 – T1 Nasopharyngeal cancer	**#2** Ashley – 46 – T1 Cancer in the neck	**#3** Brian – 52 – T2 Tongue cancer	**#4** Jean-Claude – 31 – T1 Tumour in the oral cavity	**#5** Katrina – 41 – T1 Lump in her neck
				
#6 Nell – 71 – T1 Neck cancer	**#7** Norman – 55 – T1 Cancer as 'corrupt DNA'	**#8** Scott – 48 – T1 Cancer in neck cyst	**#9** Jean-Claude – 31 – T2 Cancer cells multiplying	**#10** Ashley – 46 – T2 Post-treatment cancer
				

Table 22 - Basic details of patients' verbally conveyed images (explicit and implicit). Quotation marks denote participants' own words.

[NB – Not every characteristic of each image is cited in this table.]

Participant	**Image of the cancer**
#1 Steve – 52 Neck (unconfirmed)	"A mass of cancer cells" in his neck But the cells are formless in his mind – it is an abstract notion: "I don't know what a cell looks like so I cannae say 'oh it's that'."
#2 Andrew – 43 Tonsils	"To me, I have my tonsil there and there's a wee bit been growing out the tonsil… that's what's touching against the back of my tongue and throat, hence why I still have cancerous cells in my body – they didn't all come out with the tonsil." The "tumour" in his tonsil was "just a lump – a lump within a lump". The cells however were formless in his mind.
#3 Alasdair – 54 Throat (unconfirmed)	"I have this image of a chain-reaction of cells that are dividing… and basically, like weeds developing in a vegetable patch, they're spreading quite quickly." But, like Steve and Andrew, the cells are formless in his mind, and he cannot conceive of what they look like.
#4 Eric – 70 Tonsils	Did not envisage the cancer as a mechanical site – was an abstract concept. Cancer cells are visually inconceivable – "It strikes me as just a lot of dust flying around in the air and it's all nasty."
#5 Gary – 50 Tonsils	"A wee growth" on his tonsils which was impeding his throat and swallowing, so that any food/liquids "had to go either side to go past it". No further characteristics.
#6 Olive – 76 Larynx	A "swelling"/"lump"/"growth" situated "between my two cords that was stopping them closing." No further characterisation, very basic image, virtually identical to Barry's.

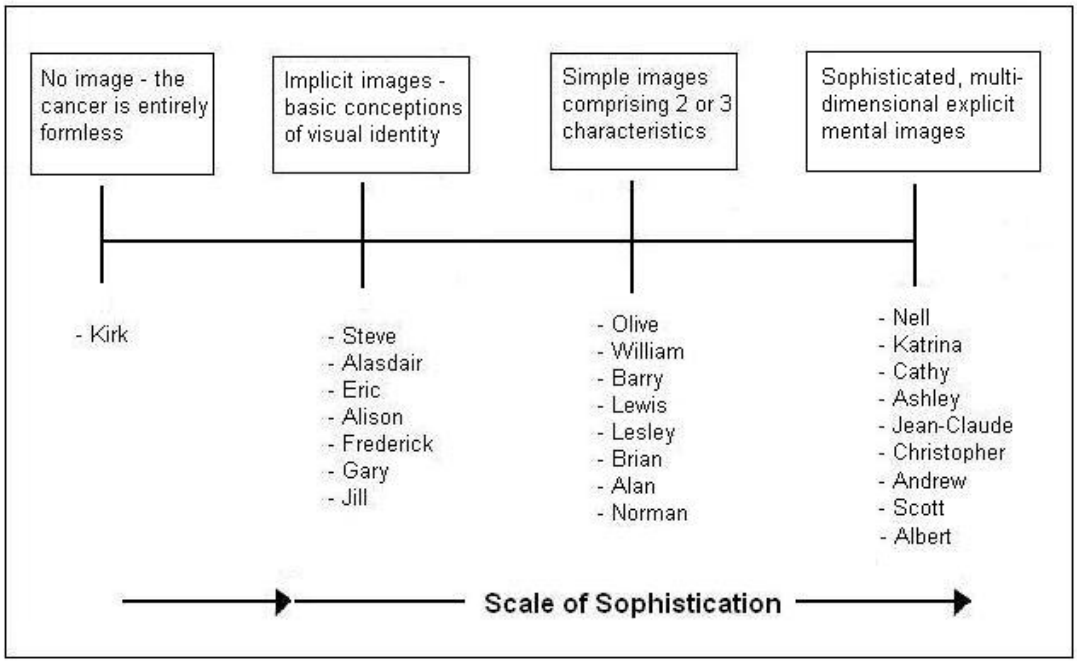
#7 William – 69 Oral cavity	Metaphorical image only – "like black ink spreading". Had no concept of what the cancer 'really' looked like: "I just can't imagine it."
#8 Barry – 69 Larynx	A little "tumour or nodule" on the vocal cords. This "little bump or spot" was protruding or "sticking out" so the cords "couldn't vibrate correctly". Very basic, no further characterisation.
#9 Cathy – 48 Tongue	Two images: a) what the cancer 'really' looks like, and b) metaphorical. "a big, deep, dark gorge" which was visible on the underside of her tongue. "Wee germ bug things" which were "ferociously" "eating away my tongue". These were mocking, "sinister" and "evil" in nature.
#10 Alison – 72 Larynx	Simply "a lump" at the back of her throat. No further characterisation.
#11 Lewis – 71 Larynx	"A wee bit sticking out" of one side of the voice-box – "just like a piece of gristle or something". Entirely derived from image seen on the monitor during a nasoendoscope examination – no embellishments.
#12 Frederick – 65 Tongue	"A conglomeration of mutated cells… growing at a fantastic rate." Located as "a big lump" at the back of his tongue. The cells themselves were formless however, he could not describe them.
#13 Lesley – 56 Larynx	"Black bits" on the larynx. Speculative thoughts re shape only. Basic and unembellished image, derived purely from HPs' language and symptoms experienced.

#14 Christopher – 56 Oral cavity	Visible part like a "white truffle" where it "burst through" the gum, this appearance was its "outer coating". Internally, the larger part of the cancer was "like a sausage without its skin", "just a mass inside you".
#15 Albert – 79 Larynx	A "small growth" visible on the vocal cords, which also has "roots" beneath the surface. Both parts of the cancer "grow bigger and bigger", and thus it was comparable to a plant in this respect.
#16 Jill – 60 Throat	"I just imagine it like a bit of rotten meat". It was a bit of her "flesh" that was "going off, rotten". Extremely basic, she had no further ideas about the cancer's form.

9.2.3 IMAGE TYPES

There was enormous variation in the level of clarity and sophistication of the images reported by patients – from sophisticated, multi-dimensional mental images to the most basic notional ideas of what the cancer was like physically. Figure 11 below represents the simple-sophisticated spectrum of mental images. The term sophistication denotes how detailed patients' images were, that is the number of characteristics – size, shape, colour, texture, anatomical location – which were assigned to each representation of the cancer. The remainder of this section will discuss these images in accordance with this scale.

Figure 11 - The scale of image sophistication



It is necessary also to clarify a couple of terms which will be used when referring to different types of image. As indicated in Table 21 and 22 presented earlier, some participants conceived of their cancer in terms of cells, and this is referred to subsequently as a 'cellular-level' understanding. Often in addition to this, the cancer was regarded as a single entity, that is a holistic structure – in some instances composed of

cells, in others referred to simply as a 'tumour' or 'lump' for example. Where patients conceived of their cancer as both a cellular structure and an holistic entity, it is defined herein as having a 'dual-identity'.

Another distinction between image types is 'realistic' or literal versus figurative. The prevalent type of mental image reported was realistic in that it represented what patients actually believed their cancer to look like (not in terms of being scientifically accurate). However a small number of patients did convey images which were figurative (non-literal) in nature, and some characteristics of the realistic images were defined by participants as having a figurative meaning. Figurative images of the cancer are dealt with in the latter part of this section.

9.2.3.1 SOPHISTICATED MENTAL IMAGES

Vivid, multi-dimensional mental images of the cancer were reported by nine of the twenty-five participants. These tended to be founded on concrete origins as perceived by the patients. All of these patients were either able to see the cancer, had a palpable lump, or experienced high-impact symptoms – that is symptoms that disrupted everyday activities and were thus impossible to ignore, such as difficulty swallowing, loss of voice, or significant pain.

Most of these patients developed their images primarily based on visual information received from third-parties. Such information, coming from a source perceived as more knowledgeable than the patient, was accepted easily in the context of their own inferior understanding:

> "You know, if somebody said, 'This is a tulip. That's what it looks like', you're not going to challenge it." [Jean-Claude T1]

> "I was at the doctor's surgery and the poster was on the wall. I saw that and thought oh that's what it is."[Ashley T1]

For two of these patients a cellular-level understanding of the disease complicated matters when discussing their images of the cancer. These patients reported sophisticated mental images of the anatomical location of their cancer, but as they could not visualise the actual cancer cells, did not therefore define their images as 'images of the cancer' despite the fact that they were quite concrete and salient in terms of their understanding of the disease.

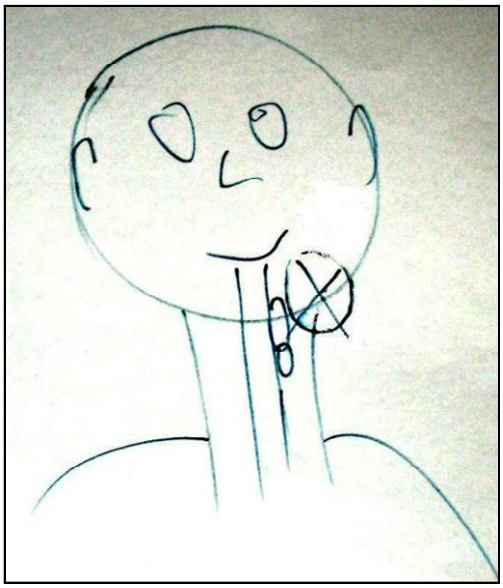
> "But in terms of you know, trying to imagine what a cancer cell you know [chuckles] looks like physically, or under a microscope you know or like a little amoeba or something like that you know it's, I, I certainly haven't projected any visions of what in the hell it looks like… And I wouldn't really want to try and draw it because I wouldn't have a clue what to draw" [Andrew, T1]

> "But the actual cells, the cancer cells have-, I really can't picture them. And one of the reasons I can't picture them is that if somebody showed me a normal cell under a microscope then I might, you know, I might hazard a guess that, y- you know, cancer cells are a different shape or misshapen you know, but it's pie in the sky." [Scott, T1]

The dual-identity of cancer did not inhibit the ability to visualise it as a rule however (see the case of Norman, in next section). Indeed most of the participants referred to their cancer on both a holistic basis (i.e. 'tumour', 'growth') and a cellular level interchangeably, though most visualised it as a holistic structure and not on a cellular level. The exceptions to this were Steve and Alasdair, who, despite presenting with a palpable lump in the neck, had only the most abstract notions of 'cancer cells', and did not perceive it as an entity at all. One possible factor in this is that both men had an unknown primary, that is the precise location of the cancer had not been determined.

9.2.3.2 SIMPLE IMAGES COMPRISING 2 OR 3 CHARACTERISTICS

Amongst our sample, images tending towards the less sophisticated end of the scale were more prevalent. Simpler images tended to be composed of only two or three parameters, such as shape and size for example, and chiefly represented the anatomical location of the cancer. Simplicity should not be interpreted as equating to low importance however.



Left: A simpler image drawn by Alan (T1), depicting the location of his cancer. The 'x' marks the spherical tumour which he could feel at his jawbone/neck, and is drawn roughly to scale. To the left of the main cancer are 2 smaller tumours in his neck.

The fact that fewer characteristics were assigned to some images also did not necessarily indicate less concreteness, and simpler mental images still reflected patients' beliefs and provided a physical identity for the potentially abstract 'cancer' diagnosis.

> "Well as I say your larynx comes down in a V and the spot I saw was on I think the left hand side which is a little bump on it… Just a little bump. Just a little spot." [Barry, T1]

Norman was unique in this sample as his mental image of the cancer was molecular, in the form of 'corrupt DNA'. A scientifically-minded man, this beyond-cellular conception illustrates that a solely cellular notion of the cancer is not necessarily diametrically opposed to an image of it. Notably, none of the patients who talked about their cancer as both an entity and on a cellular level had any image of the cells themselves about which they felt any degree of confidence – they could only speculate.

9.2.3.3 **IMPLICIT IMAGES - THE MOST BASIC NOTIONS OF VISUAL IDENTITY**

At the far end of the sophistication spectrum were those who did not acknowledge a mental image of the cancer, but who throughout the interview referred to it in consistent visual terms which was suggestive of an underlying implicit image. As a general rule these patients had only the most simple conception of the physical form of the cancer – as a 'lump' or 'growth' for example – and did not imbue it with any other characteristics.

> "A conglomeration of mutated cells… Something that shouldn't be there multiplying rather quickly and stealing the nutrition from the good cells, and killing off the good cells at the same time." [Frederick, T1]

There was often a degree of uncertainty about exactly what the cancer was, or where it was located, in these instances. Kirk was the only patient who lacked any kind of concrete concept of the cancer, referring to it only as "a tumour", but in quite a meaningless fashion – a label he used without any conviction regarding what it was, more as a synonym for the term 'cancer'. His was an almost entirely abstract understanding of the cancer.

9.2.4 FIGURATIVE IMAGES

Some patients also conveyed non-literal, figurative images when talking about the cancer. These images could be abstract, metaphorical or based upon similes. The role of such figurative images within the interview context appeared to enable them to communicate their understanding of the cancer. Interestingly, even those patients who reported no mental image of the cancer itself employed visual language when talking about their cancer - again suggesting that patients may have a more tacit conception of what is going on inside their bodies in the form of an implicit image.

> "It strikes me as just a lot of dust flying around in the air and it's all nasty. It's like the weed-killer out there that I use in the work, you know." [Eric, T1]

> "I've done a little bit of reading on it, and I, I do understand that cancerous cells are those which multiply faster, or divide faster, than other normal cells. So I have this kind of image of a chain-reaction of cells that are dividing, em… and basically [coughs] like weeds developing in a vegetable patch - they're spreading quite quickly. Em, but then in, in order to eradicate these weeds, it's also in some cases necessary to eradicate the vegetables too." [Alasdair, T1]

Only one patient reported a wholly figurative explicit mental image of the cancer. Cathy, who was also able to see her oral cancer, imagined it as like the "germ bug things" from a recent Domestos advertising campaign, during which the animated bugs laugh about making people sick – and the cleaning agent is how to eradicate them. This image was rooted in the rapid growth of the cancer she witnessed, and conveyed her feelings about the cancer in terms of its perceived power in contrast to her own vulnerability and fear.

> "Like a sinister thing, like erm … 'yeah you know we've got a grip on you now!'… Erm that's how I think, I thought about it and everything because I could see it getting worse and worse, and feel it getting worse and worse… I would say it … you know like I say these little you know germs, whatever you want to say, obviously I mean I saw how quickly they attacked my mouth, that how quickly and how ferocious they could have you know moved on to other parts of my body… Erm, and I just think that as I mentioned just earlier the funny germ like laughy kind of evil creature… Just all in my neck, 'let's go for the node things!' - almost like that, you know in my neck." [Cathy, T1]

The Domestos bugs remained relevant for Cathy at the follow-up interview, though her own understanding had evolved of why this image represented the cancer. She later realised it was the cruel timing of the cancer, which ended a period of rare happiness in her life, that was really symbolised by the bugs' laughing, mocking nature.

> "The wee bug things represented to me the cells and the bad cells, the cancer cells, and it was almost like they were just, 'ha, ha, ha'. The black gang had kind of jumped onto the good cells or the good guys and bashed them a bit and that's

what they're kind of laughing at and almost like at the time… Everything was so happy and that was somewhere where I'd never been so I can't remember when for years… So for me to be in that place and be so happy and so like 'this is fantastic', for me to be told what it was… Inside, I was probably thinking, well, a part of me was thinking, 'well, you've had it really good and you thought everything was wonderful but this is just a wee reminder to say that…' - but that's probably to do with my own insecurities as well - that from me thinking that I had everything, and then all of a sudden, bang, it's like, this kind of evil thing had come in." [Cathy, T2]

9.3 BEHAVIOURAL IMAGES: CHARACTERISING CANCER

Patients' mental images of the cancer were distinguishable as cellular or entity type conceptions, in many cases a combination of the two. Their images could be further categorised by the perceived nature of the disease in terms of its behaviour – the cancer conceived of as either a destructive force attacking the body, or as a 'rival' life force within the body. This was the only characterisation by which meaningful differences between the two groups could be discerned. This section will first define these two concepts and then provide an overview of the apparent differences between the groups.

9.3.1 CANCER AS DESTROYER

The 'destroyer' characterisation signified a belief that the cancer was actively attacking the healthy, non-cancerous structures within the body. Nine of the twenty-five patients identified the cancer as having a destructive disposition. Reflective of traditional cultural notions of cancer 'eating away' at bodily tissues, the cancer was perceived as 'taking over' or destroying the body's normal cells.

> "There was a big lump… I'm assuming that the leakage caused damage to the main nerve on this side which affected the muscle which would have killed off the muscle like, you know. And so there's been glands obviously [removed] and muscle tissue which was killed off because the nerve had been killed off, you know, with the leakage like, you know." [Steve, T2]

> "I think cancer is a sort of wastage of something, it's a wastage, maybe there's a weak part of the body and somehow or other it gets attacked by this cancer." [William, T1]

For one patient the concept of cancer as destroyer appeared to be heavily influenced by the fact that she could see the cancer develop on the underside of her tongue in a manner which seemed to erode it.

> "I could actually see it. It was almost like it was eating into it. You could just see this kind of black… the longer it was left, you could see it getting deeper and deeper, almost like eating the tongue away almost." [Cathy, T2]

Another potential influence over this was a punitive belief that the cancer was attacking not just Cathy's body, but her as a person. The cruelness of the timing of her illness, and the feeling that she was being 'reminded' that she did not deserve happiness is explicated in an excerpt on page 286 of this chapter (the 'figurative images section). Such a belief may seem more congruent with a destructive characterisation than a life force characterisation, however the one other patient who felt their disease was a reflection of her need to be punished was in fact in the latter group.

Ashley: "I see it as a punishment……If I had been stronger Rachel wouldn't have killed herself, that's what I get for being weak."

Researcher: "You blame yourself for that?"

Ashley: "Oh absolutely, absolutely... …I think I could have talked her out of killing herself there and then… …that's how I feel, the cancer is a punishment."

[Ashley, T2]

This reinforces the complexity of the construction of mental images. There is no A = B = C, and patients' interpretations of the cancer are not easily categorised. There were also no discernable difference between the two groups in terms of whether patients believed the cancer was part of their own body or some kind of foreign matter which had 'arrived' – beliefs about this split evenly in each group. Therefore the body was equally capable of destroying itself as it was of being destroyed by the presence of an external, invading force.

"It's the body turning against me. The DNA's been corrupted and it's slowly poisoning me and creating tumours and eventually well, it'll do its job and that'll be it." [Norman, T1]

Most of the patients who attributed a 'destroyer' quality to their cancer envisioned this in terms of it attacking other bodily tissues. For one patient the destructive behaviour of the cancer was limited to specifically to the lymphatic system, an understanding embedded in his beliefs of how cancer could eventually cause death. In this instance the presence of the cancer in the lymph glands would compromise the cells of the immune system, eventually destroying it.

> "I'm not sure, but I think because it's travelling through the immune system, that [coughs] ultimately what would happen is it would destroy most of your immune system, and in, in that case, you're more likely to [coughs] to er, expire from a secondary infection of some kind… … ultimately if it's travelling through the lymph gland system, it's ultimately going to affect your bone marrow which produces the, the cells that you require to keep healthy. If it spreads into that, then you're into areas like leukaemia and so on, em, and your immune system will just dissolve." [Alasdair, T1]

9.3.2 CANCER THE LIFE FORCE

Alternatively the cancer was conceptualised as a second, rival life force within the body, an entity not necessarily unlike the other organs. The threat in this instance was in the interminable growth of this life force, which was competing with the existing bodily structures for space, rather than actively attacking them.

> "Well I just assumed it was just like a vegetable growing. Once it starts, it expands." [Lewis, T2]

> "All they're basically doing at the moment is stopping the thing progressing and hopefully killing it off… once you've got a tumour, obviously it gets bigger it'll not get any smaller. I don't know if your own body system could challenge it ken." [Kirk, T1]

All of the participants remarked on the progressive nature of cancer as a disease, growing increasingly larger. With regard to the destroyer characterisation, this meant that more of the body would be 'damaged' or taken over; whereas in the latter instance

the cancer was growing in its own space rather than taking over, and this would eventually impede the functioning of other structures.

> "All I thought is that it was growing and as it grows it's going to then start causing problems for other parts of my neck but obviously windpipe, back of my nose, breathing problems, that was-, it was going to get bigger until it was causing blockages and difficulties in breathing, swallowing, whatever." [Alan, T1]

> "Oh I could imagine how it would have- it would just get, the roots would get longer, bigger, and it would just fire out a… well then your voice box it would choke you I suppose … …That's how I feel like. You can see a tree or a flower with a little root, growing bigger and bigger and bigger. I see it that way. I think it's the same idea." [Albert, T1]

Sixteen participants imbued their cancer with a life force orientation. For two of these patients however, they perceived the disease as primarily static – that is while demonstrating a life force characterisation this aspect of the cancer, its behaviour, was not particularly salient in their conception of it. Perhaps significantly, both of these patients exhibited a lower level of concern about the cancer following the receipt of reassuring information. In one case this was a perceived decreased risk of the cancer spreading, and in the other it was the belief that the cancer was eminently treatable in contrast to her prior expectations, demonstrated in the excerpt below.

> "When I first was told it was cancer I never really thought about it, I just thought, I thought whatever it was shouldn't have been there and it arrived, I think it was, I don't know if I thought it was growing or whatever… That's because they said to me it's one of the better places to get it because it is quite treatable… If they'd

said [it was] in my lung like my husband I'd have been in a bit of a state I think." [Lesley, T1]

At face value the non-destructive nature of the life force characterisation may seem less frightening or distressing than the destroyer, a possibility which may be supported by the apparent general difference in the level of anxiety between these groups (outlined in the concluding part of this section). However that is not to say that a life force orientation was inherently non-threatening, and this was certainly evident amongst those participants in this group whose cancer was incurable.

Ashley: "It is just sitting there like that, pulsing in the corner."

Researcher: "You think it would be kind of pulsing?"

Ashley: "Yeah… malevolently… [like] 'What else can we do to her?!'"

[Ashley, T2]

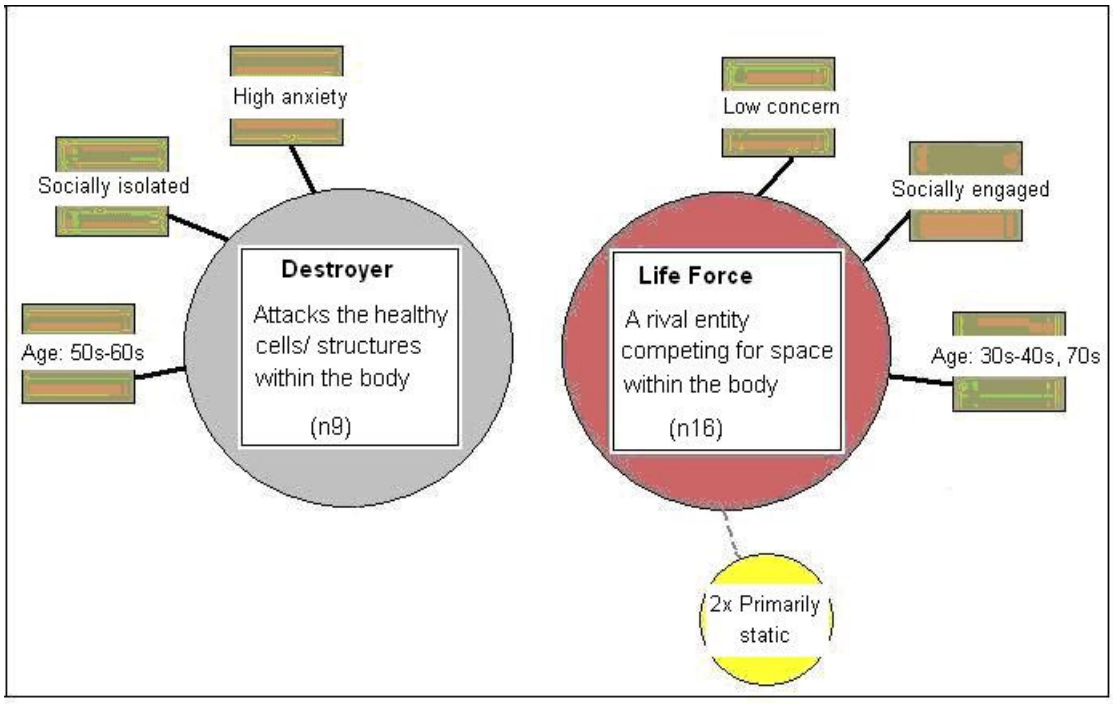
The inevitability of the resurgence of the cancer in terminal cases, where it was a life force of such potency it could not be extinguished, translated to a sense of helplessness and powerlessness. This is emphasised in the excerpt below from the only patient who transcended the destroyer/life force categories. Christopher primarily conceived of his cancer as a destructive force yet this encompassed a strong life force element, and so his cancer was simultaneously attacking and dominating his body.

"It would be more like an amorphous mask, just something that takes the shape of its available surroundings I think, then obviously when it starts growing it will, like I say it will, you know presumably push the softer stuff away or grow round things or grow up things or round them or whatever, like ivy growing up the side of a building, it will take the shape of whatever's there." [Christopher, T2]

9.3.3 DISTINCTIONS BETWEEN THE DESTROYER V LIFE FORCE GROUPS

As intimated at the start of this section, perhaps the most interesting aspect of these two concepts of the cancer was the differences between the groups in terms of age, level of anxiety, and social engagement – as indicated in figure 12 below. These disparities were discovered during the process of distinguishing between the characterisations of the cancer, when a pattern in terms of the anxiety patients had exhibited during the interviews became apparent. This led to further investigation of how numerous factors were represented in each group, from which the differences in the age profiles and level of social engagement were detected.

Figure 12 – Tentative differences in some features of participants between groups



The analysis in this respect was crude, consisting of comparing the prevalence of different sample characteristics/beliefs in relation to the numbers in each group. An example is the proportion of patients who believed the cancer was a part of their own body compared to those who believed it was a foreign body which had somehow

'arrived' inside them. Five patients from the destroyer group favoured the 'part of own body' conception, alongside eight patients from the life force group. Given that the ratio of patients in each group was approximately 2:1 (16 life force, 9 destroyer), these figures represent an essentially even split, and thus no difference was apparent. Other factors such as gender, location of the cancer, sophistication of the patients' images, and the treatments undertaken did not appear to differ notably – the categories being evenly represented/showing little numerical difference between the groups, or comprising too few patients to allow a meaningful comparison.

The difference in the age profiles of each group was readily evident, with a predominance of the youngest (30s-40s) and oldest (70s) patients in the sample in the life force group, and those in their 50s and 60s in the destroyer group, and this is explicated in table 23 below.

Table 23 – Age distribution according to characterisation group

Age Group	**Total no. Participants**	**Destroyer characterisation**	**Life Force Characterisation**	**Proportion Split- 9 : 16**
30s – 40s	7	●	●●●●●●	1 : 6
50s – 60s	12	●●●●●●●	●●●●●	7 : 5
70s	6	●	●●●●●	1 : 5

Given that a destructive quality is perhaps more congruent with traditional cultural perceptions of cancer as an attacker, 'eating away' at the body internally, it was interesting that all but one of the participants from the oldest group held the opposing, non-destructive view. Meanwhile the grouping of most of the youngest patients in the life force group is possibly suggestive of the changing social perceptions of cancer as a disease, the improvement in survival rates and reduction in the prevalence of the 'cancer

equals death' belief; though the distribution of the eldest participants clearly does not support this notion.

More compelling were the apparent differences in anxiety and social engagement/ isolation, however there is a major limitation in terms of these associations. While the distinction in age profiles was incontrovertible, the categorisation of participants by levels of anxiety and social engagement was not based on an objective measure. No quantitative assessments were incorporated into the interviews, despite the availability of tools to measure these, as these factors were not originally a focus of the study which was wholly qualitative in design. Participants were therefore categorised in these respects in a qualitative manner, based on their interview transcripts and the notes made by the researcher (field notes) during and after each interview. These field notes contained observations about the participants as well as reflections on the interviews themselves, for example the researcher's impressions of the interviewee's demeanour, the atmosphere, their response to particular issues, or impressions of their home life. This kind of contextual information then aided the analysis and interpretation of the transcripts, and also informed the subjective assessments of participants' levels of anxiety and, in particular, social engagement (as much of the information pertinent to the latter was revealed during the conversations prior to and after the recorded interview). Some excerpts from these field notes will be presented in this section to illustrate the kinds of observations upon which participants were so categorised.

The main problem with this process was the inability to categorise each of the twenty-five participants due to insufficient indications of the patients' anxiety/social status in some cases. Given the already tentative nature of these apparent patterns in light of the lack of objective assessment, it was deemed important that any categorisation of participants be based on sufficient indicators from the data available to enable the

researcher to be confident in these. Therefore only those participants who clearly exhibited high anxiety or low anxiety (n16), social isolation or a high level of social engagement (n18), could be defined as such, and therefore these reported patterns are tentative at best. Table 24, below, clarifies the distribution of classifiable participants according to these categories in the destroyer and life force groups.

Table 24 – Levels of anxiety and social engagement distribution according to characterisation group

	Total No. Participants	**Destroyer Characterisation**	**Life Force Characterisation**	**Proportion Split- 9 : 16**
High Anxiety	10	●●●●●●●	●●●	7 : 3
Low Concern	6	●	●●●●●	1 : 5
Socially Isolated	7	●●●●●	●●	5 : 2
Very Socially Engaged	11	-	●●●●●●●●●●●	0 : 11

As Table 24 shows, a total of sixteen participants exhibited sufficient anxiety, or lack thereof, during the interviews to be categorised on the scale of high anxiety – low concern. Seven of the nine patients in the destroyer group appeared to be very anxious, concerned about a range of issues from their prognosis to the administration of treatments. In addition, of the six participants who displayed a highly pragmatic, undaunted attitude to their situation – linked heavily to a perception that the cancer was 'minor', and their prognosis favourable – only one conceptualised the cancer as a destructive force.

Data excerpts suggesting a high level of anxiety:

> "So I mean… where would it spread to-, if I left it, if I say to them I don't want any treatment at all, so what would happen to me, you know. Would it do this, would

it stay in my gum or on my jaw or would it go up to my brain or what? I think it would go to my brain, I think, you know, because the brain's such a delicate thing and it does so much doesn't it?" [William, T1 – destroyer group]

"Well any part of your body, cancer is a terrible illness, it's an illness that doesn't ever get shoved to the back of the mind. I'll never put it to the back of my mind, it will always be there and I'll always fear it if it comes elsewhere." [Alison, T1 – destroyer group]

Field Notes: 'The interview was pretty difficult. Jill struggled a lot to talk about the cancer, giving only brief answers to many of the questions but repeating certain concerns several times (loss of weight/voice, curability). She is being treated for a recurrence of the throat cancer she had a couple of years ago and was very anxious – "pretty daunting" – and stated "not thinking too much about it" was one of her coping mechanisms, and think this palpable fear/desire to avoid could be factors in her lack of forthcoming-ness throughout.' [Jill, T1 – destroyer group]

Data excerpts suggesting a low level of concern:

Researcher: "I wondered as well about once your radiotherapy's finished do you see a time when you'll be back to sort of normal-,"

Barry: "I hope so, I certainly hope so. I'll have to wait and see. I might get worse."

Researcher: "Is that one of your concerns, that you might-,"

Barry: "No. But I just, it's one of those things isn't it? I'll either get better or I won't." [Barry, T2 – life force group]

Lewis: "I guess its just one of those things. I am genuine when I say I am not worried."

Researcher: "Yes? You're not putting on a front for me?"

Lewis: "No, oh no." [Lewis, T1 – life force group]

Eighteen participants were classifiable as either socially isolated or demonstrating a high level of social engagement. Social isolation was not determined according to marital status or whether the patient lived alone – which did not differ significantly between the groups (proportion 3:5, all 25 participants classified). Rather the transcripts were scrutinised for evidence of a sense of isolation, a lack of involvement in social activities[5], or a lack of social support/contact with family and friends, and it was notable that five of the seven isolated participants characterised the cancer as destroyer. This skewed distribution is further emphasised by the fact that all eleven participants who were very engaged socially – in terms of having a high degree of contact with family and friends, or reporting involvement in social activities such as a fitness class or bowling club – were in the life force group.

Data excerpts suggesting social isolation:

Field Notes: 'Lives with and cares for his poorly 86y/o mother. Never married, no children, Describes being 'quite distant' from siblings, and 'independent'. No longer works and financially secure, but his work base was elsewhere – now he struggles to care for his mother, keep the house while having treatment. Enjoys 'good food, gardening', but quite cut off from other people due to responsibilities as carer and lack of close family.'

[Norman, T1 – destroyer group]

[5] The lack of social engagement referred to here does not mean simply a temporary loss of the ability to take part in social activities due to the cancer/ treatments – something which was reported even by highly socially-engaged patients. Rather it was a lack of involvement socially in one's typical life, irrespective of the limitations imposed by the cancer and treatments.

"I didn't socialise much anyway to be honest. No I didn't. I don't have a big social life anyway so I'm not missing that aspect of it in a way."

[Christopher, T1 – destroyer group]

Data excerpts suggesting social engagement:

"In fact 99% of my pals have been magic about it, really great… when we get together even like – can't get a beer. I can't get a beer yet with the morphine, I'm not allowed to drink. When we get together… we'll have our initial conversation, we'll ask – everybody'll ask, we'll have ten minutes at the start of the night, how's Chris, how's he getting on, what's the latest new and then we drop it, we get on… And I'll have a normal night with the boys." [Alan, T2 – life force group]

"Oh I'm back to the gym and back to the dancing, oh yes I'm back to everything, yes, yes I'm back to everything." [Olive, T2- life force group]

Field notes: 'Lives in a village with husband and 2 daughters, and runs after-school clubs for children. Close-knit and close-proximity family and in-laws, and her friends "have been here all the time, all the time". Was mid-baking for fund-raising event when arrived, and has been involved in several other events over past year or so (with friends). Has a very active, busy life with lots of different people in it.' [Katrina, T1 – life force group]

Despite the acknowledged limitations of the way patients were assessed in terms of anxiety and level of social engagement, these apparent distinctions between the destroyer and life force groups are thought-provoking nonetheless. It is not possible to state on the basis of these findings with a small sample whether this apparent pattern in

the data means there is a link between how the cancer is characterised and the anxiety experienced, whether the former is determined by the latter, or indeed whether a significant relationship exists between these two factors at all. All that can be gleaned from this qualitative study is that there appears to be a pattern in this data, and the potential nature of the relationship between anxiety, social isolation, and the destroyer/life force orientations can only be speculated about at this stage, for example whether people who are socially isolated experience greater anxiety, are thus more likely to conceive of their cancer as a destructive, malevolent force. These questions may warrant further attention however, and how this could be accomplished is revisited in the following chapter.

9.4 THE ORIGINS OF PATIENTS' IMAGES OF CANCER

Three different sources were identified as influencing the construction of mental images of the cancer. The most prominent influence appeared to be the information supplied by health professionals, in terms of their use of visual language and exposing patients to material images of the cancer. The symptoms experienced, that is the presence of detectable lumps, or the ability to see the cancer, alongside participants existing beliefs about the body and the nature of cancer, also played a role in how they envisioned it.

9.4.1 VISUAL LANGUAGE AND CLINICAL IMAGES

In the context of cancer and its treatments as uncharted territories, information provided by health professionals (HPs) was often treated as gospel by participants and easily accepted. As with the pilot study, this information was identified as the key influence over how patients visualised their cancer. Images that participants were exposed to in the clinical setting included the visual descriptive language used by HPs, and pictures of the cancer/affected area in the form of scans, internal images witnessed on the monitor

during nasoendoscope examinations (where a small camera is inserted into the nose and down the throat), and diagrams or photographs shown to them. Where the cancer was hitherto an abstract notion in patients' minds, such images appeared to form the basis of a more tangible cognitive representation of it and enabled patients to generate a mental image of the cancer. While in instances where patients had already constructed a mental image of their cancer, exposure to clinical images often resulted in modification of these pre-existing images. Patients' mental images tended to be open to change in this manner on receipt of new information, and this is one form of evolution, which is delineated in part four of this chapter.

Visual information such as this appeared to 'stick in the minds' of patients, who exhibited a high degree of awareness to where their images of the cancer originated:

> "And then I had a camera down my nose and down my throat and they discovered this, a bit like a pea, that's what they said like." [Albert, T1]

> "The first time they put the thing down my nose, I had heard them saying something about three black spots to the doctor, whatever they were looking at, three black spots, I am presuming that's it." [Lesley, T1]

> "I just really imagined-, I mean his drawing was just a sort of 5cm by about 3cm growth and that's just really how I looked at it." [Brian, T1]

Sometimes verbalised or clinical images were internalised verbatim – for example Brian did not embellish the image of the cancer provided from the HP's sketch at all, nor did

Ashley, whose primary image came from a poster. Verbatim images like these were still subject to change in accordance with patients' changing perceptions of their disease however.

9.4.2 APPEARANCE AND TEXTURE OF THE CANCER

A small number of patients could either see or feel their cancer. Visible cancer would generally form the basis of how patients visualised their cancer, but these patients' mental images were not necessarily confined or limited to what they could see. For example in Cathy's case, the visible 'dark gorge' on the underside of her tongue gave rise to a secondary, figurative image which represented the cancer's menacing nature. All Christopher could see of his cancer was a small white blemish on his gum, but from this he generated a comprehensive image of the extensive internal part of the cancer, which he believed had a different appearance to the part which was visible.

Palpable swellings provided patients with notions of size, shape, and texture:

> "I just thought it was a round … something round and fleshy… Like squashy, something that you could like squeeze, yeah… That's what it felt like 'cause I could move it about, it wasn't just solid." [Katrina, T1]

9.4.3 EXISTING BELIEFS

Patients' existing understandings of the body, and beliefs about the identity of their illness – i.e. 'what cancer is' – also played a part in shaping the mental images they constructed:

"I mean I don't know, it is just some sort of growth that … that's there and it's a lump I presume as everybody says but that's only because you hear folk saying I found a lump." [Olive, T2]

" I mean pretty much any tissue that we have that's not really skin, I mean it's all blood you know, any tissue you can say everything's red, it's the same. To me it would just be a continuation of the tissue that's already there you know… You see a bit of surgery, you see someone cut open, they're red be it within the cheek, within the leg, within the stomach. It's all red." [Alan, T2]

9.5 PART TWO: IMAGES AND UNDERSTANDING CANCER

Cancer was conceptualised as a serious, progressive disease. Most participants had a concept of the cancer growing or developing over time, and it was known as a disease which, without intervention, would prove fatal. It may progress in myriad ways: growing larger, spreading locally, or spreading extensively via the bloodstream/lymph nodes.

The cancer was regarded as growing either as an entity expanding, or through the more specific multiplication of cancer cells. The impact of continual growth on surrounding structures was not necessarily clear to patients, though almost all cited some basic notion of what the cancer was 'doing' inside their bodies. Those who had experienced symptoms which had worsened over time understood the growth in terms of impeding normal functioning, for example Alan described it as:

"I can only imagine it's closed off a part of the cavity in the back of my nose which has stopped me having that function in my left nostril. So the fact that's now

> shrinking a little, it's allowing me to breathe. That would suggest it's retreating back to its space from whence it came allowing what should be there to expand back into its normal shape again." [Alan, T1]

This was congruent with his symptom experience, and he expected his breathing to return to normal once the cancer was eradicated, i.e. there would be no internal damage beyond temporary 'squashing'.

Other patients did perceive the cancer as causing damage to their normal tissues as it grew, either by actively attacking and 'killing off' good cells, or consequently invading and taking over normal tissues through its growth.

> "Obviously the bad cells are growing and taking over an area, destroying whatever it's affecting like you know… I'm assuming it's attached to fleshy bits, and it's – whether it's eating away or em, just affecting, you know spreading, killing off good cells" [Steve, T1]

Spread of the cancer was also considered an inevitable progression of the disease if not treated early, and was one of the consequences most talked about and feared by patients. While a number of patients expressed uncertainty about the precise mechanism of spread, all had theories about how it might happen. Approximately half of patients envisioned the cancer spreading simply through physical contact or closeness between tissues, or via continual growth:

> "I assume that it's a continuous thing, you know, from the start and it goes into all these places. Now I don't imagine that it becomes separated really it's just all

there. It's growing all the time and it's growing to another fresh area, gradually taking over everything." [Nell T2]

The most-cited method however was by invasion of another bodily system through which it was perceived it could travel, namely the bones, the bloodstream, or the lymph nodes. This mode of spread represented a greater threat to patients as the spreading was not confined to the local area and the cancer had access to all the organs of the body – it could literally go anywhere.

"Well my understanding is if it's in the bone marrow and it's in the bloodstream then it can basically go anywhere." [Norman T1]

"Of course if you get it into any of the lymphs it could spread anywhere. When it gets to the liver then you get really worried." [Frederick T1]

9.5.1 IMAGES AND ILLNESS BELIEFS

Even the most basic mental images of the cancer appeared to embody and thus reflect patients' beliefs about it, particularly regarding the perceived consequences of the disease. Patients' beliefs and their mental images appeared to have an interactive relationship, and this – together with consideration of whether the beliefs or the mental image comes first – is explicated in Chapter 10. The most salient of these beliefs and their correlation with specific attributes of the mental images or other kinds of images will now be described – the perceived link between location and size of the cancer and severity, and the envisioning of colour as representative of the identity of the cancer and its personal significance in the lives of patients. Drawing on the ways in which patients'

beliefs are embedded in their mental images of the cancer, this section will go on the demonstrate the emotional power of images by referencing instances where visual information has impacted on the level of fear inspired by the cancer. This is particularly poignant in the case of participants who were facing a terminal diagnosis, and mental images in this context will also be outlined. The section closes with a brief commentary on the unpredictability of cancer in the minds of participants.

9.5.1.1 LOCATION AND SEVERITY

There was a strong link between the understanding of the anatomical location of the cancer and its severity in terms of prognosis and the likelihood of it spreading to other areas. Mental images aside, the belief that head and neck cancers were less serious than organ cancers was reasonably widespread within the group.

> "You know so, again that's why I'm not really down about it. If it was in my liver or kidneys or anywhere you know, bowel or anything like that, you know to me that's serious cancer" [Andrew T1]

Fear that the cancer may have spread was most potent before patients received a definitive diagnosis, and the existence of any spreading was an important marker of increased severity. As organ cancer was generally perceived as more serious, some patients drew comfort from the belief that it was less likely to spread to the organs due to its more distant location:

> "I think er, having it in my vocal cords it er… minimalised it. If it'd been in my body it could have gone anywhere, you know."[Albert T1]

> "The location of it means that it shouldn't spread and they could get at it. It's not as though it's in the centre of your body or anything like that." [Brian T1]

The perceived severity of the cancer was not determined solely by its location however. Even where this was deemed to be favourable, the size of the cancer and the extent to which it was believed to have grown was also related to notions of severity.

9.5.1.2 SIZE AND SEVERITY

Cancer was identified as a progressive disease, continually growing, and threatening to spread. Larger cancers were therefore perceived as more established and advanced, and thus more difficult to treat – requiring more aggressive forms of treatment – and so size was correlated to severity. In this context, gauging the size of the cancer was one of patients' primary concerns. Even those with unconfirmed primary cancers (suggesting that the disease was not confined to one area) interpreted size as particularly meaningful:

> "But it must, must be quite small because they can't locate it with the biopsy, and they can't locate it with the camera and so on… So that's, that again is relatively hopeful." [Alasdair, T1]

> "It probably would've helped to see you know the, the area that they were talking about like. Just to see maybe how far, you know what- to what extent, what area it had covered, the actual main bit…" [Steve, T1]

One patient, Alan, cited fear of discovering the cancer was larger than he thought, and the negative implications of this on his ability to cope, as the prime motivation in his

deliberate avoidance of any real images of the cancer (outlined more fully in a subsequent section).

9.5.1.3 COLOUR, IDENTITY AND MEANING OF THE CANCER

The colour of the cancer was reported by less than half of the patients, and for some, colour was a less concrete or prominent aspect of their mental image. There was remarkable accord between the 11 patients who did ascribe a colour to their cancer however, with only two variations – 'realistic' body tissue coloured (e.g. red, flesh-coloured, pinkish), and black.

Patients who were able to either see their cancer directly, or who had seen images of it recalled the colour accurately. Even where this was not this case however, a number of patients imbued it with a 'realistic' bodily colour. This reflected their identity beliefs about the cancer as being part of their own body, as opposed to some foreign entity which had invaded their body. As part of the body its colour was then likened to that of other organs, or 'reddish' like anything else inside the body.

> "I can only visualise it as I saw it there, and that's because you'd imagine anything like that to be red wouldn't you, because it's to do with your veins and bloods… Like an open wound, you'd expect it to be red." [Ashley, T1]

> "Like a heart or a liver or a kidney, that kind of, it needs a blood supply so presumably it is blood supplied colour, like every other organ, it's like a mini organ isn't it I would imagine." [Chris, T2]

Four patients described their cancer as black. This was based on its real, visible colour in one instance; and on an overheard reference to 'black bits' by health professionals in another. For two patients the use of this traditionally negative colour reflected more their feelings about the cancer, and their belief in its virulence.

> "I would think it's a sort of like, it must be like black ink spreading, you know. That sort of thing, some sort of thing spreading and they may be able to zap it with this radio thing, you know. That's the only think I could sort of say, yes. I think it may be some sort of fluid or something that's spreading." [William, T1]

To put these remarks in context, it is important to note that William was very depressed at the time of the interview – angry and confounded by the diagnosis, anxious about the treatments, and afraid that he may die. The black colour is consistent with this devastation, and the fluidity of the mental image as ink which is spreading is indicative of his feeling of helplessness and fear of what might happen.

Norman eloquently explained why the cancer (the corrupt parts of his DNA) would be black. In the context of a terminal diagnosis, black was associated with conveying his feelings of powerlessness and profound sadness

> "It shows that light has been absorbed and not reflected, you know, like a dark star. Don't go near it or else you'll never get out, you know, like a black hole… It doesn't radiate anything. It just absorbs, it takes in and devours and that's why it would be black." [Norman T1]

9.5.2 THE EMOTIONAL POWER OF IMAGES

As the previous section illustrates, in addition to reflecting patients' feelings about the cancer, images communicated positive or negative messages about its seriousness to patients. In the absence of a concrete mental image of the cancer it may be harder for patients to formulate specific expectations as they 'don't know what they're dealing with', as the tangibility of the images patients' constructed appeared to enable them to understand the specific nature of their disease more clearly by removing their conception of it from the abstract level - and thus negating some of the uncertainty.

Many of the patients in this sample reported their mental images as purely factual and evoking little in the way of an emotional response. However, the emotional power of mental images lies in the fact that the images are 'realistic' in nature and can therefore inspire fear, or reassurance, and in a number of cases this impact was the direct result of visual information For example a consultant's sketch of the tumour instilled confidence in Brian about the likelihood of a positive treatment outcome by reducing his fear of the cancer spreading and providing him with a less threatening representation of it.

> "He showed me dimensions of it and I was able to contain in it that bit. I thought right that was there, that's only where the cancer might become – that it can attack in whichever way surgery or chemotherapy, radiotherapy and it was much better, much easier to focus on something like that than on something that was invasive, more invasive… …Right, it is in that little box… I can deal with that little box, it is so much easier to deal with." [Brian T2]

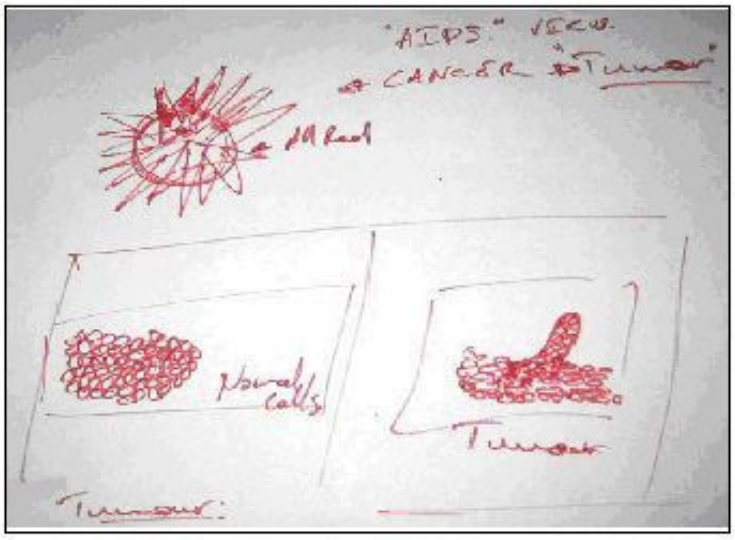
Where the patient has an existing mental image of the cancer, information which contradicts it, if taken on board, can too effect a change in patients' perceptions of their

disease, and hence their emotional state. This is well illustrated in the following two excerpts. Albert had been diagnosed with early stage larynx cancer and was relatively confident of a good prognosis, expecting surgical removal of the "growth" to be an end to it. When he learned following surgery that radiotherapy would be necessary "to get the roots of it", this caused an increase in concern about the seriousness of his cancer as having roots beneath the surface raised the possibility of the cancer spreading:

> "Oh I could imagine how it would have- it would just get, the roots would get longer, bigger, and it would just fire out a… That's how I feel like. You can see a tree or a flower with a little root, growing bigger and bigger and bigger… Take a hold, aye. And then it's difficult to- the bigger it got the harder it is to get it removed… That's it, that's how I look at it, definitely." [Albert, T1]

A more positive impact was observed in Jean-Claude. Originally his tumour was represented by a figurative image – a symbol which was used to represent AIDS in the 1980s (top picture, below) – a spiky red ball used by the media which evoked panic and fear:

> "I would basically see that and then a little square picture on the side of the man's face when he talks. There would be this picture of the cell, the big red cell with spikes and you think 'Oh my God, this is it, we're all going to die!'"
>
> [Jean-Claude, T1]



[Jean-Claude, T1]

Exposure to a diagram in a patient information leaflet (bottom picture, above) showing a bed of normal cells next to an identical one with a tumour composed of abnormal cells protruding from it some time later inspired quite a different reaction however - simply factual and unemotive.

Limiting the amount of information sought was cited by a number of patients as a coping strategy. These patients would accept the information offered without asking further questions, even where there were gaps in their understanding, as their goal was either to avoid thinking 'too much' about the cancer, or to avoid becoming more anxious by learning unsettling information. Equating the size of the cancer to its severity led to specific avoidance of visual information for one patient. Alan conceived his tumour as approximately 2-3 inches in diameter, and exhibited considerable fear of dying, especially poignant as he had two small children. The size he envisioned the cancer to be was 'scary enough' and he tried to avoid any real images of it in case it proved to be even larger, which he knew would increase his fear and doubts about treatment efficacy:

> "I've tried not to think about the size of it, thinking 'that's huge, how are they going to shrink that?' you know." [Alan, T1]

The containability of the cancer was a key feature in reducing fear as much of patients' anxiety was regarding the possibility the cancer could spread. Scott's cancer was located within a cyst in his neck. For this reason he did not worry about the size of the cancer itself, as most did, and felt secure enough while it was contained in the cyst.

> "I was quite happy for the cyst to get as big as it wanted… as long as it was sort of encapsulated within the cyst I was-,the only legible worry that I can ever think or doubt was the lymph nodes because once the lymph nodes get involved it can be pretty horrendous. It can be pretty fast and it can be, you know, and that was it. the actual size of the cyst because in the end it doesn't matter if the cyst is the size of a pea or the size of a football, if it's encapsulated within the cyst and it's not migrated from the area it doesn't make any different. It's all aesthetics and the size of the operation you're going to have." [Scott, T1]

Andrew's mental image of his cancer as having originated within the tonsil, then grown out of the bottom of it and spread to the back of his tongue/throat ratcheted up his anger at the delay in his diagnosis because of the perceived increased seriousness, and again containability was the key feature. As he explains:

> "The only frustration or disappointment I have throughout this whole thing with the medical profession was, was that guy…Who cost me two months. Because then you start thinking well, if the cancers which are still currently in my body are a secondary infection, did they happen – could the two months have stopped that

> happening? Those 2 or 3 months that he's cost me, could it have been wholly contained within the tonsil?" [Andrew, T1]

Few patients could actually see their cancer, but where it was visible, for example inside the mouth, patients were left in no doubt as to its development or progression, and where this was perceived as rapid it increased fear.

> "I could see it getter darker and darker and the actual nature of it was black erm underneath. Erm and so for me it was like this just horrible, I could actually sit there looking at it… I could see it getting worse and worse, and feel it getting worse and worse." [Cathy, T1]

Other types of responses to real images were scant, though a degree of disgust did register in a few instances, for example as Ashley described her reaction to the poster image:

> "It looked a bit yuck, looked a bit horrible." [Ashley, T1]

The strongest emotional reactions to mental images of the cancer – where these images had an impact emotionally – were when they either provided reassurance or inspired fear. And importantly cases like that of Brian who was shown a sketch by the consultant demonstrate that patients' mental images are susceptible to new information and can potentially be altered to reduce distress. This susceptibility is outlined in part four of this chapter which describes the ways in which patients' images evolved over time. For the majority of patients however their mental images of the cancer, while reflecting their beliefs about it, did not appear to elicit particularly powerful responses. The images were purely factual, accepted, and not dwelt upon in any depth.

9.5.3 IMAGES IN THE CONTEXT OF TERMINAL CANCER

Four of the participants had been informed their cancer was incurable. Mental images of the cancer were particularly powerful in these circumstances where they related to how cancer actually kills a person. Nell visualised her cancer as a pulsing heaving mass of cancer cells which were growing progressively and gradually "filling up" her neck. The eventual result of this she imagined would be that it would constrict her windpipe and would effectively strangle her.

> "I sort of visualise it as a reddish mass… [puts hand up to throat to indicate choking herself]" [Nell T1]

And the anticipation of this was the key source of her fear:

> "I'm actually a bit scared about that… That's the one thing that does bother me when it comes back but that's how I can-, I sort of see it as a thing that's getting bigger and bigger and bigger and then it's taking up all the space." [Nell T2]

Christopher's prognosis changed during the interval between the interviews when the cancer returned after completion of treatment, and he was told it was incurable. The unstoppable progression of his cancer he expressed as follows:

> "I would imagine it would be like anything else, it would take the easiest route and the path the least resistant to begin with. Like anything else growing like a, you know like a dandelion root will you know grown in between paving stones and if there's cement there it will take a route to the right and down, so I can imagine that's something similar… if it meets something stronger it will move round it, maybe that's why it's so deadly because they grow around something rather than try and fight it, it will just try and find another way round it and then cut off, cut it

> off both sides rather than one or surround something completely and things like that, you know until it's strong enough to do what it wants." [Christopher T2]

In contrast to the majority view, the location of the cancer heightened Ashley's fear of spread to the brain due to its close proximity. This was particularly distressing as she planned to take her own life rather than endure the indignity of a slow deterioration, and she feared the impact of any spread to the brain might render her incapable.

> "Being mental impaired, when do you know the right time to end it …So that's the bit where you are thinking when do I jump? You know, so you have to keep an eye on yourself all the time. Obviously I am not thinking tomorrow but I have to keep that in mind that if I start feeling myself losing the plot then I have got to seriously consider what I am going to do." [Ashley, T1]

9.5.4 THE UNPREDICTABILITY OF CANCER

The experience in its entirety was epitomized by the notion of having to negotiate 'uncharted territories' in which the path is unknown and both cancer and the treatment process are cloaked in uncertainty, and all of the findings herein must be understood in this context. Patients were aware of the highly variable nature of cancer and the impact of treatments – both are unpredictable to varying degrees – and so prior experiences of the disease do not quell this uncertainty, and fear and anxiety tends to be high.

Cancer as a disease lacks a straightforward linear trajectory – it affects different people in different ways, lacks a definitive end point, the pathway through it is uncertain and the outcome not always predictable.

> "You know there are so many different types. Some are worse than others, some are curable, some are containable, some are not curable" [Alasdair T1]

Essentially much of the uncertainty was focused around the consequences of having cancer, and combined with the knowledge that it is a potentially life-threatening disease can prove difficult to cope with:

> "I mean I know there are different types of cancer but cancer's cancer and I thought that's it, that's the end. I thought it was my time here to go but apparently, then I started seeing this radiotherapy and all this and all help and all this. I don't know if it will clear up or not but I just, it's not a nice feeling at all. It's just upsetting." [William T1]

Likewise, the outcome of treatments cannot be guaranteed, something which concerned even those patients whose prognosis was favourable, and the anxiety over this and the possibility of recurrence, was palpable:

> "They sort of tell you it's curable and it's- they've caught it early – first system, first grade - early system. You have an idea 98-99% cure, but you cannae say never-, never say never." [Albert T1]

> "You can go for a few years without any problems and then, you know, the little devil's still lurking around there. So yeah, it's-, I don't think that's ever going to go away. It's always going to be a fear, a small fear of some kind but,-, that it will come back." [Alasdair T2]

9.6 PART THREE: IMAGES AND UNDERSTANDING TREATMENTS

The newness and strangeness of the experience of having cancer, of it being largely 'uncharted territory' for patients, outlined in the previous section, is also applicable to the experience of treatments. Cancer treatments again comprised a world unknown to participants. All patients reported having at least heard of radiotherapy and chemotherapy before their diagnosis, though very few felt they had had a credible understanding of them prior to their own treatment, and most claimed they didn't really know what to expect. Treatments were believed to be brutal, and the lack of any frame of reference increased anxiety, a fact that was recognised by the patients themselves:

> "…The first time you got it done you just [think] 'oh hell'. You just go into this room with this machine with a table and the table is like only half soft, the top half is very, very hard and I had my head up in this thing and it isn't comfy either… …The initial, the first time I think would be scary because you don't know what to expect." [Lesley, T1]

The uncertainty surrounding treatments was three-pronged. Initially this concerned the nature of treatments, that is the practical side of undergoing radiotherapy or chemotherapy – the process by which it administered, and the clinical environment. The second facet was the perceived Russian roulette of treatment side effects. The majority of patients appeared to be well-advised about possible side effects, yet were aware also that these varied between individuals, and were unsure as to the severity of their impact. Finally the efficacy of treatments, whether they would achieve the desired outcome, was a cause for concern. Even where patients perceived the prognosis to be favourable the effectiveness of treatment was not taken for granted, and many sought

confirmation of efficacy throughout the treatment process by monitoring their changing symptoms.

The variation between individuals in terms of the degree of certainty about these aspects was enormous. A number of patients reported few expectations concerning any of these issues, while others had absorbed information and felt at the outset that they had a clear idea of what to expect in terms of likely side effects or how the treatment was administered.

The practicalities of receiving chemotherapy or radiotherapy treatment were for the vast majority a completely new experience. This aspect of uncertainty was only short term however, patients very quickly adapted to the hospital environment and the treatment schedule/process and became au fait with it.

The uncertainty over the impact and efficacy of treatments was longer lasting however, and in many cases could not be quelled by information-gathering. The key issue was the conception of treatments as affecting people in different ways – in terms of both their success and the side effects caused. This was remarked upon by nearly all of the participants, who realized that individual variance was large and much depended on how their body responded to the particular treatments.

> "I have a rough idea of what's gonna happen. Well I know the specifics or the mechanics of all of these tubes and so on but, I'm – I don't know exactly what the outcome of all these treatments is going to be, you know, it's generalisations, cause each, each person reacts in their own unique way to it." [Alasdair, T1]

9.6.1 SURGERY

Thirteen patients in the sample underwent at least one surgical procedure. These ranged from excision of the cancer itself, removal of an entire internal structure containing the cancer (e.g. a tonsillectomy), to more extensive surgery like a radical neck dissection which involves removal of all possible soft tissues - muscle, fat, lymph nodes etc - from part of the neck area. Surgery to remove the primary tumour was generally carried out at the beginning of treatment schedules. Following radiotherapy and/or chemotherapy, some patients then underwent a neck dissection as a final stage in treatment.

By the time of interview, the majority of patients appeared to have a clear understanding of the nature and extent of their surgery, and expressed this fluently. In terms of how patients' visualised their cancer, surgery produced relatively straightforward adaptations to their mental images, for example being reduced in size, or one part of the cancer being excised. The mechanics of surgery held little mystique for patients - it was simply 'this was cut out' or 'this was removed'. And compared to radiotherapy and chemotherapy, about which there was greater reference to visual concepts, surgery was generally easily grasped.

9.6.2 A PRIME ROLE FOR IMAGES IN THE UNDERSTANDING OF RADIOTHERAPY

All patients in the sample underwent radiotherapy: for six it was their sole treatment, six had it in conjunction with chemotherapy, five in addition to surgery, and eight patients' regimens consisted of all three treatments.

Radiotherapy was conceived by all patients as specifically directed to the site of the cancer, though it would damage all tissues in its path, including non-cancerous cells, which

were expected to later regenerate. From this, patients understood the need to be kept still during each session so they could target the correct area – hence the mask. A few patients cited a secondary protective function for the mask, believing it was also to help to shield the rest of your face from the harshness of the radiotherapy.

In the absence of any visual or sensory cues during administration, radiotherapy was identified variously as 'beams', 'rays' or 'lasers' - which give it a form, and perhaps more cryptically 'x-rays', 'radio-waves', and simply 'radiation'. A number used more than one of these terms interchangeably, and there was a high degree of unity regarding the central identity of radiotherapy as an invisible, controllable substance which could be directed at the cancer, regardless of the precise terminology used.

The knowledge of radiotherapy as a targeted treatment, and the purpose of the mask to 'mark the spot', gave rise to gun-related images as patients envisioned how it entered the body.

> "It does it from the top and it's actually shooting straight down and then-, well, mine was the bottom first usually and then the top." [Scott, T2]

The action of the radiotherapy on the cancer was most embedded in images, and despite a high degree of expressed ignorance about how it worked, all bar two patients had formed some kind of impression. The majority of patients described it as 'burning' the cancer cells, though the precise nature of the burning was not always clear, and this was expressed in myriad ways:

> "I mean I don't really understand. What I think happens is it burns – whether this is true I don't know – it burns away the swelling that's there, or decreases it somehow, shrinks it there" [Olive, T1]

> "I just thought it would be like the microwave at home, it cooks from the inside outwards. And if they've gone in there destroying the cells or cooking them or whatever they're doing with them I don't know, that's just the thoughts." [Barry, T1]

The perceived burning notion was heavily linked to the anticipated/experienced redness of the skin external to the irradiated area - a side effect of radiotherapy akin to severe sunburn:

> "I just assume it burns it out…The last time my neck was all burnt I suppose."
>
> [Jill, T1]

Some patients cited other symptoms which reaffirmed the idea of its burning action on the cancer, for example Jean-Claude and the delayed irritation of the skin:

> "Well the burning sensation comes, I guess it's like if you burn yourself, you don't feel it when you burn it, you just feel it after, so I guess it's the same principal as the laser, it burns after." [Jean-Claude, T2]

And Lesley's experience of coughing up mucus:

> "Well I am thinking because it had been burning my neck, it was burning it, and I think well, it is like burning a bit of paper, you know if you burn a bit of paper, it

> falls off... Just like that, and I just thought well that is what is happening and it has come up and this is the coughing and spluttering" [Lesley, T2]

'Zapping' and 'shrinking' were also identified as mechanisms of action by smaller numbers of patients, though these were not preclusive of an underlying notion of burning. Two patients put forth a distinct alternate action, that of 'scraping':

> "It's obviously very raw, it's been scraped away and that's pretty much how I think of it as sort of that whole area gone over with a wire brush or something." [Brian, T1]

> "To me the radiotherapy on my throat was like an internal chemical peel, you know. It was taking everything off. That's my understanding of it. I don't know how accurate that is or not so it was horribly gooky, browny, yellowy, whitey horrible stuff." [Andrew, T2]

Notably, Andrew's was a T2 only conception – he had cited a zapping or burning effect at T1 – and indicates a change in his understanding of how radiotherapy worked in line with new side effects experienced. This is one kind of evolution which is discussed more fully in part three.

There was no linkage between the perceived identity of radiotherapy and a specific mechanism of action. For example in case of the six patients who primarily conceived radiotherapy as 'beams' or 'a laser', the action was cited as shrinking, scraping and burning, and was unspecified by one. One potential explanation for this is the interchangeable nature of identity labels – that is the terms generally lacked any

distinctive meaning, but represented a core notion of radiotherapy as an invisible substance which could be precisely targeted to attack the cancer.

9.6.3 IMAGES EXPRESS BELIEFS ABOUT THE NATURE OF CHEMOTHERAPY

Fourteen patients received chemotherapy as part of their treatment schedule. Chemotherapy was described variously as toxic chemicals/poison/drugs in fluid form – all essentially the same thing, reflected by the interchangeable use of the terms – which circulated throughout the body and 'killed off' good cells as well as cancerous ones (though the good cells would later regenerate).

> "They apologise for poisoning you in a kind of joking, jocular kind of sense but that's in effect what they're doing, is putting toxic material into you to kill cells." [Alasdair, T2]

The perceived drastic action of chemotherapy, its indiscriminate attacking nature, was expressed through simile and metaphor by patients:

> "It kills cells in the body, not just cancerous cells but healthy cells as well. It's just a bit like letting the army loose instead of the police and they're going to destroy everything they come into contact with." [Norman, T1]

> "Come the end of the 21-day period, they expect the body to be back to a normal process, ready to… to be beat up again like yeah(!)" [Steve, T1]

In contrast to radiotherapy, whose action was vividly perceived by patients via visual concepts, the method by which chemotherapy killed off cancer cells was unclear to most patients, though a number described it as 'shrinking' the cancer – something which appeared to have been taken literally from HPs' explanations of the purpose of the therapy.

> "I'm not really sure about it but when they said 'oh we'll give you the chemotherapy, that'll shrink it, you'll be able to swallow.'" [Nell, T2]

The shrinking type of action was the only real visual concept employed in patients' understandings of chemotherapy. One explanation for this is that, like surgery, the nature and process of chemotherapy is relatively straightforward and lacks the element of mystique that radiotherapy has. It has a tangible, visible identity, and (perhaps like many drugs) its exact mechanism of action is not something patients thought about:

> "It's a drip in your vein." [Katrina, T1]

> "I understand it is pumping chemicals through your body… really how it works I don't know." [Ashley, T1]

The comparative dearth of visual concepts evident in patients' understandings of chemotherapy and surgery as treatments themselves, lends support to the hypothesis outlined in the next chapter - that images may develop as one facet of the mind's attempts to understand the situation. Where these two treatments are easily comprehended by patients, the need for visual concepts to facilitate understanding is

lesser. By contrast the intangibility of radiotherapy lends itself to the employment of images as patients try to 'fill in the gaps' in their knowledge, and form a coherent understanding of the treatment process they are undertaking.

9.6.4 ARE TREATMENTS VISUALISED IN THE SAME MANNER AS THE CANCER?

In relation to the mental images of the cancer which tended to be discrete, and relatively concrete and complete in form (whether explicit or implicit), the treatment-related images described here – rather than representing a clearly defined, complete understanding of the treatment – conveyed specific aspects of patients' understandings. These images appeared to act and exist in an ancillary manner dependent on the mental image of the cancer. That is to say such images primarily reflected the perceived impact of the treatment on the cancer, for example the 'burning' action of radiotherapy or 'shrinking' action of chemotherapy, and did not seem to be visualised independently to the mental image of the cancer. In contrast to the complete or definitive mental images of the cancer, treatments were often represented by multiple, complementary visual conceptions of its identity and action.

For example the apparent inter-changeability of the identity labels patients applied to radiotherapy, and the lack of any kind of relationship between the perceived identity and specific mechanisms of action, does suggest that treatments were represented visually in more fragmented terms, with different images embodying different beliefs. Collectively however these multiple distinct images seemed to reflect a consistent underlying understanding of radiotherapy as an invisible substance which could be precisely targeted to attack the cancer.

Treatment-related images then appeared to differ subtly in form from mental images of the cancer as they did not constitute complete or definitive representations – rather

particular aspects of patients' beliefs; and because they were inter-dependent with the patient's singular, complete mental image of the cancer. Given these posited distinctions, images pertaining to treatments are characterised in nature as visual concepts embedded in language which conveys realistic or figurative images, rather than discrete mental images which can be visualised in the mind's eye (though they could arguably also be understood as implicit mental images). This interpretation is discussed further in the subsequent chapter.

9.7 PART FOUR: EVOLUTION

Patients' images of both the cancer and the treatments combine to enable them to understand what is happening inside their bodies over the course of their experience. In considering how patients' understandings and images evolve, there were two key questions:

1. Do patients visualize their cancer differently at T1 and T2?
2. How do patients' mental images and understandings of the cancer evolve over time?

This section will address these questions – it will outline the enduring nature (stability) of patients' original mental images of the cancer, and detail the ways in which these evolve as patients incorporate the perceived impact of their treatments, and assimilate selected new information, into these images.

9.7.1 STABILITY OF MENTAL IMAGES

Patients' original mental images of the cancer were generally stable across time – that is the same image of the initial cancer was referenced by patients in interviews at T1 and T2. Only in one case, that of Jean-Claude (pictures on p331), was an original image

replaced with an entirely new one, and this was related during the T1 interview as having occurred in the time before the first interview. The secondary image became a functional, realistic mental image of his cancer, though he stated that the primary, spontaneous mental image would always be associated with cancer in his mind, despite this change. As he explains:

> "If you were going to ask me what I think cancer looks like, if you look at the leaflet that they send you, I think that's the first time I realised maybe I wasn't thinking about it the right way. The leaflet that lady gave me is like, normal cells, abnormal cells of tumour and, it's kind of like, we are drawing a tumour growing of different cells. Before, and I don't know why because it's a kind of … the idea of what cancer would have looked, would have been say in the Eighties, right, AIDS was quite big. And, AIDS, I don't know, because it doesn't seem to be presented this way any more, but it was represented by this red ball with loads of spikes coming out.
>
> …That's how AIDS was represented, as a virus. Maybe it was just in France and it was this drawing. And it was just this ball with loads of, like, you know, just loads of spikes coming out, physically. Red ball, loads of spikes and that was AIDS. And that was the virus, that was the idea of like it was something weird, dangerous, or anything like that. And I would have thought, it's just how you put pictures in your mind, but that's how I would have represented cancer. I'd see that evil drawing of normal cells, abnormal cells of tumour, whatever. But that's how I would have represented that in my head." [Jean-Claude, T1]

Images which represented treatments were also typically stable, with very little change in patients' understandings of it at T1 and T2, though patients did report varying levels of detail at each interview.

9.7.2 THE PERCEIVED IMPACT OF TREATMENTS

The perceived impact of treatments, embedded in visual concepts as outlined previously, represented the most significant form of evolution of patients' mental images of cancer as patients incorporated this into their images - combining these beliefs with their mental image of the cancer in order to mentally 'keep track' of the progress of their treatment regimen. Patients' mental images evolved in accordance with their beliefs about the purpose and outcome of treatments – beliefs again derived chiefly from information imparted by health professionals, and to a lesser extent influenced by their experience of changing symptoms or side effects.

For the six patients undergoing only one mode of treatment - radiotherapy only – their mental image of the cancer underwent the fewest reconstructions, its evolution consisting simply of three stages: the original cancer image, the impact of the radiotherapy, and the outcome image of the cancer or site post-treatment. This is illustrated by the case of Lewis. He was retired man in his 70s being treated for laryngeal cancer, who reported a very simple mental image of his cancer based on a photograph of it he was shown during a consultation.

Image of the Cancer		Impact of Radiotherapy		Outcome Image
The photograph showed the larynx from above, and the cancer was "a wee bit sticking out", protruding from one side of the voice-box, which was "tiny, conical-shaped", and "looked red" next to the "pinkish" colour of the larynx. It looked to him "just like a piece of gristle or something growing where it shouldn't be."		"Kills off the cancer cells", "burns out the cancer".		The cancer is simply gone, and the larynx back to normal.

[Lewis, T1]

The example above outlines the most minimal form of evolution of mental images amongst patients undergoing single-mode treatment regimens. Five of these patients had early stage larynx cancer and were being treated with a curative aim. Their original mental images of the cancer were very simplistic in nature, and all bar one conceived the cancer as 'just gone' following radiotherapy, with no thought to how it actually happened (the exception was Lesley, reference later in the 'dead cancer' section).

The complexity of the evolution of patients' mental images increased not just with the number of different treatments patients received, but in accordance with a) the perceived persistence of cancer in the body throughout the treatment period; and b) perceived variations in treatment impact.

The surgical patients were split half and half in either considering their cancer 'gone' and all follow-up treatment of a precautionary nature, or that there were still cancerous cells in their bodies post-operatively and further treatment was necessary to completely eliminate it. In terms of evolutionary impact on patients' mental images of the cancer, it was typically less complex for the former group, as the notion of lingering cancer cells was a theoretical, not concrete, one.

> "Apparently they're just going round about where they cut to make sure they've got everything…Just to make sure." [Jill, T1]

> "So that's why they also wanted, they were quite keen, to do a bit of chemotherapy to try and mop up anything that he'd missed… It was more as … better to do it than not do it… Just in case. He said because he couldn't get up quite as far as he wanted to do and he would have preferred to go a bit further but it was bigger than he thought." [Christopher, T1]

Having had the cancer removed – "like the eye of a potato" – Jean-Claude was unique in his conviction that his precautionary radiotherapy was not in case of any remaining cancer cells, but to purposely kill off the good cells which were present while the tumour was there:

> "To me, it's out. This is the thing where I don't have cancer any more… I'm guessing, right, to me, this is burning cells which were there when the tumour was there. Until new cells are recreating themselves, when the tumour is not there… So, in theory, it's all clean." [Jean-Claude, T1]

Where the persistence of cancer post-surgery was not in doubt, patients' mental images of the cancer were subject to more extensive modification. The following example shows how Andrew's initial mental image of the cancer as extending from the tonsil to spread locally evolved post-surgery to reflect the remaining problem and need for further treatments.

> "I mean, mine was in a lump cause it was in my, my tonsil… So you know, it was a lump within a lump. So em, in terms of envisaging what it looks like, I mean to me you know, I have my tonsil there and then there's a wee bit will have been growing out the tonsil – to me that's what's touching against the back of my tongue and throat, hence why I still have cancerous cells in my body, em, they didn't all come out with the tonsil." [Andrew, T1]

As outlined previously, radiotherapy and chemotherapy were distinguished by patients according to their contrasting natures (targeted to an area versus circulating throughout the body) and perceived differences in their mechanisms of action. Most patients receiving both treatments believed the overall impact on the cancer itself would be like for like – i.e. chemo and radio- therapy would ultimately affect the cancer (and hence their image of it) in the same way, despite these differences.

> "There are two lots of radiotherapy; one was a general one that at that area and the other was targeted at specific bits and again I visualise it in much the same way as the chemotherapy that it scrapes away lots of good, bad and indifferent stuff on the basis that the good will grow back and the bad won't." [Brian, T1]

However six of the fourteen patients assigned chemo- and radio- therapy different purposes and believed each of these treatments impacted on the cancer itself in different ways. The majority view was that chemotherapy reduced or shrunk the cancer, and halted any further progression, and then radiotherapy was employed to attack and actually kill off the core cells.

> "There's the chemo there zapping it up say. It could be, I don't know. There's the chemo there keeping the cancer cells down, and then the radiotherapy coming in to 'puff'." [Gary, T1]

> "Chemo as far as I'm concerned is designed to shrink the tumour. That was my understanding, the chemo's there, designed to shrink it and the radiotherapy is there to pretty much zap the cancerous cells with good doses of x-ray and kill them off completely." [Alan, T1]

A key influence here was the almost immediate impact on symptoms – for example a reduction in the size of palpable lumps in the neck – following patients' first one or two sessions of chemotherapy. Patients who distinguished between radiotherapy and chemotherapy in this way incorporated an additional dimension into the gradual reconstruction of their mental image.

9.7.3 WHAT HAPPENS TO THE 'DEAD' CANCER?

Twenty of the twenty-five patients did not venture any theories about how the cancer came to be extinguished from the body when not fully excised surgically. In the majority of cases it was simply 'killed off' - 'gone', and patients did not question the mechanics of it – or if they did, it was not dwelled upon.

> "That was definitely shot at the right-, where they reckoned the-, there was a heap like a beehive or something like that sitting there and it just killed-, like a wasp nest and it just killed them all or something like that, you know." [Eric, T2]

> "It must be killing off the cells, what happens to the cells after that I dinnae ken. It must be blasting them somewhere or other like… It must be killing off a few at a time." [Kirk, T1]

Five patients did puzzle over the issue, though this did not appear to cause any distress or anxiety.

> "I don't even know what happens to the dead cells, you know do they, do they automatically just like evaporate or are they flushed out the system way like so, it's something that I've never asked … Em, and I'm assuming that treatment, the drugs, the radiotherapy that I'll, I'll have, will you know just banish it all, you know make all the, these bad bits er, disappear." [Steve, T1]

Alasdair interpreted the advice to keep well hydrated during chemotherapy as more than just good for your general health and 'keeping your system flushing', but necessary to 'flush out' the dead cancer cells through the kidneys:

> "Em, I'll have to drink loads and loads of liquid because those dead cells have to come out your body somehow… So you flush them out. Em, so that's another thing, I drink about 3 litres of water a day, to try and flush out what I presume are the, the dead cells floating around in there… Because they have to go, have to go somewhere. And that's, that's, that's what I picture is happening anyway." [Alasdair, T1]

Particular symptoms were also suggestive of dead cancer to a couple of patients - Lesley believed the black mucous she coughed up following radiotherapy to be bits of

the dead cancer, as it had to come out somehow; while Alan queried the nature of the nosebleeds he experienced following chemotherapy, but did not reach a firm conclusion:

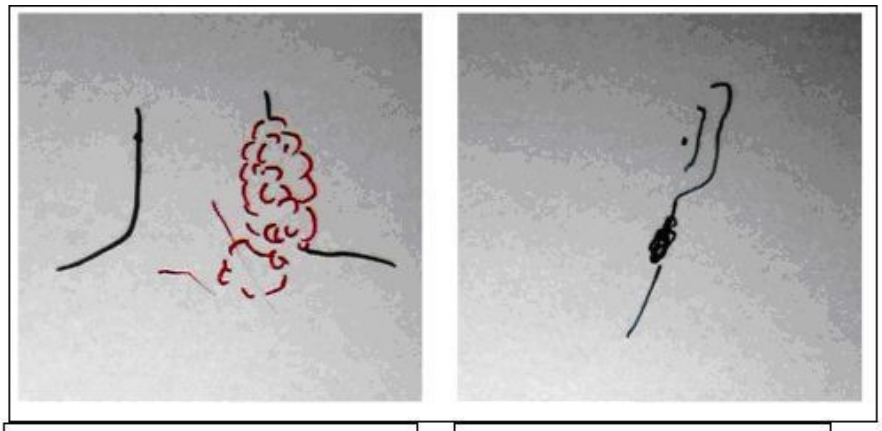
> "I had a few nose bleeds after chemo for the first two weeks. Not so much nose bleeds but as you blow your nose there'd be a bit of blood on the handkerchief. But once again I think this is more – well, from my view is this is the chemo doing its work, the tumour's shrinking, it's obviously coming apart. I don't know how – obviously I don't know they physical terms or how it actually shrinks but if it falls apart, comes apart you're blowing bits of it out or if its putrefying itself or – I don't know. I honestly don't know but that's – there's always going to be some blood involved in that and generally you find sort of into the third week after chemo that would sort of fade out as well so which timed itself with the start of the next dose of chemo." [Alan, T2]

9.7.4 AN ALTERNATE EVOLUTION – INCURABLE CANCER POST-TREATMENT

Sixteen of the nineteen patients who completed both interviews classified themselves as cancer free at the time of follow-up. The remaining three patients had been informed their cancer was incurable – two were aware of this from diagnosis, and one man's prognosis had deteriorated since a recurrence of the cancer post-treatment between T1 and T2.

Nell and Ashley had received chemotherapy and radiotherapy with the aim of improving their quality of life – reported by them as to reduce the size of the cancer to enable them to eat normally. In both cases a reduction in symptoms was achieved, and so their mental images of the cancer evolved to reflect the impact of the treatments, and then beyond as they predicted the form in which the cancer would inevitably return.

Ashley was the only patient who drew her cancer at both T1 and T2, and the pictures in the box below demonstrate the evolution of her cancer as she imagined it across time.



T1 – The cancer in Ashley's neck is a mass of "pus and lumps". It is "red and pussy... [with] all veins through it and everything". This reflects her initial symptoms – a massive swelling in her neck, and the image was adopted directly from a poster she saw.

T2 – The treatments have 'shrunk' the cancer considerably. It is now "dried up and shrivelled... like a little walnut or something". However when it begins to grow back it will return to its original (T1) form.

Nell had related a clear, concrete and stable mental image of her cancer at T1 as "a heaving mass" of cancer cells in her neck which was "growing fast" and "forever on the move". She too perceived her treatments as shrinking the cancer as far as possible, but at the time of the second interview in was in some confusion over her current cancer status which inhibited the development of a clear post-treatment mental image.

> "To be honest it's difficult to say what I would say I think it's like. It's obviously not there to the same extent that it was before because they say they can't see it but that doesn't mean to say that there isn't some somewhere else, does it? …I mean before they said, you know, when you, it won't go away, so why tell me it's gone?" [Nell, T2]

The crux of this confusion was the receipt of 'mixed messages' from HPs – one telling her the cancer appeared to be gone, while another she said consistently reminded her not to forget that the cancer had 'not gone away', and she was not cured. Reports at follow-up appointments that there was 'nothing there' confounded Nell's expectations in accordance with her original terminal prognosis and information from other HPs, and while she believed the cancer would inevitably return as per its original form, she lacked any certainty over its visual identity.

> "I mean the thing is what do you believe? Do you really believe that they actually mean it's not there, they can't see it or do they mean that well, it's not too bad but of course it's still there? I don't know." [Nell, T2]

9.7.5 SELECTIVE RESPONSIVENESS

Intriguingly, as patients' understandings developed over time, there was in a few cases an element of selective assimilation in the renovation of mental images – with some aspects of new information not being incorporated into, or replacing, existing images. For example Katrina had a clear image of the cancer in her neck, but could not imagine the cancer at the back of her tongue, as she did not learn about this part until after it had been surgically removed.

In the vast majority of cases exposure to 'real' images of their own cancer had a keen influence on patients' mental images of it. A notable exception was Norman however, whose original representation of his cancer as corrupt or perverted DNA molecules remained his dominant image despite having seen the cancer at the back of his throat.

The reasons why certain pieces of information were not assimilated into patients' mental images of the cancer are unclear, but it suggests that while patients strive to understand their cancer and treatments, the mental images they generate are the product of a complex influences and peculiar to their own preferences and interpretation.

9.8 CHAPTER SUMMARY

This chapter has recounted the findings from a longitudinal qualitative study examining the role of mental images of the cancer and other visual concepts embedded in language in patients' understandings of their cancer and treatments. Patients' mental images were part of a complex mesh of beliefs about the cancer and its treatments, and were typically stable from T1 to T2, with very few changes to core beliefs. Issues concerning the definition of an image of the cancer as a 'mental image' and the extent to which people are aware of internal mental images were raised by the lack of image re-creation by participants, and it is proposed that these findings indicate that mental images may exist on a continuum being more explicit or more implicit in nature. There was a high degree of variation in the level of sophistication of mental images of the cancer – from the most basic implicit representations of form, to simple mental images which incorporated perhaps only 2 or 3 dimensions, to vivid, sophisticated multi-dimensional mental images.

The findings here support those from the pilot in terms of the responsiveness of patients' mental images – how they evolved to reflect their changing understanding of the cancer in light of the perceived impact of treatments. Mental images of the cancer were functional and reflected patients' beliefs, and the interpretation of aspects of these, for example the relation of size to severity, could increase fear or provide reassurance. The perceived behaviour of the cancer, as a destructive force or rival life force, may also be

related to its emotional impact – analysis of the patterns of these distinct characterisations suggesting, in the most tentative fashion, that there may be a relationship between the level of anxiety and destroyer v life force orientation of patients' mental images. A distinction has also been drawn in the ways in which images seem to be involved in patients' understandings of the cancer and of various treatments. Whereas the cancer tended to be represented by discrete, relatively concrete and complete mental images, treatments appeared to be reflected in multiple, complementary images which represented different aspects of patients' understandings of treatments – for example different specific images to convey the identity and perceived action of radiotherapy. Images pertaining to treatments took the form of visual concepts embedded in language rather than mental images which could be visualised in the mind's eye. This interpretation of treatment-related images outlined more fully in Chapter 10 where parallels are drawn with conceptual metaphor theory.

This chapter has illustrated that mental images and visual concepts embedded in language play an important role in patients' understandings of their cancer and treatments. One possible explanation for why patients develop mental images is in an attempt to better understand their situation – to make sense of what is going on inside their bodies – as they strive to negate the uncertainty inherent to the experience. This argument will be presented in the subsequent discussion chapter.

10 DISCUSSION AND CONCLUSIONS

10.1 INTRODUCTION

The purpose of this PhD was to explore the role of mental images in head and neck cancer patients' understandings of their illness, and gain an insight into how this hitherto neglected aspect of experience may relate to their illness beliefs and broader experiences of having cancer. The previous chapter relayed the findings of a longitudinal qualitative study which investigated the nature, form, function, and development of patients' mental images of their cancer, and the ways in which visual concepts embedded in language pertained to their understandings of the various treatments. This chapter will begin with a brief recap of the thesis as a whole and what has been learned about the ways in which patients with head and neck cancer may visualise their disease. It will go on to discuss these findings in relation to patients' experiences and comprehension of their disease, some of the methodological issues inherent to researching mental images, present some of the limitations of this project, and reflect on the potential implications for future research and practice.

10.2 THESIS RECAP

This part will provide a brief summary of the rationale and objectives of this project, and the design and salient findings from each empirical exercise. It will close with a review of what has been gleaned from the research studies concerning the ways and extent to which head and neck cancer patients have mental images of their cancer.

10.2.1 PROJECT RATIONALE AND AIMS

The aetiology of head and neck cancer means it is a disease which affects a disproportionately deprived/socially disadvantaged population. The impact of both the

cancer and treatments can result in significant functional and psychological difficulties, and this patient group are also likely to engage in behaviours detrimental to good prognosis such as continued smoking or drinking. To date there is a lack of qualitative research with head and neck patients, and so little is known about their experiences and understandings of their cancer. Yet the development of any interventions to improve outcomes for this patient group requires first some insight into how the disease is perceived and experienced by those it affects, and this project sought to gain such an insight.

The theoretical premise underpinnings of this thesis lie in the self-regulation model (SRM) (outlined in Chapter 3), in particular the concept of illness representations. Empirical work stemming from this model has consistently demonstrated that patients' beliefs about their illness factor significantly in the psychological impact of disease, and how it is managed and experienced by the patient, as well as being linked to overall outcomes. Recent research has suggested that illness beliefs may be embodied in visual form, in patients' mental images of their disease, and has indicated that patients' drawings may be a viable means of accessing these beliefs – which may in addition factor powerfully in psychological, behavioural, and health outcomes. This research study sought then to explore the role of mental images in head and neck cancer patients' understandings of their disease, and the importance of these in the context of their illness beliefs and overall experiences. Specific research questions concerned issues of how best to access patients' mental images of cancer, clarifying the origins of such images, delineating their nature and common parameters or properties, and exploring the significance of mental images in patients' comprehensions of their disease. A qualitative methodological approach was employed, and there were three empirical components to this thesis – an exploratory pilot study, a metasynthesis of existing qualitative research, and a larger

longitudinal study. The following section will recapitulate the key findings from each of these endeavours.

10.2.2 HEAD AND NECK CANCER PATIENTS' BELIEFS AND IMAGES-PILOT STUDY

The first empirical phase of this thesis was an exploratory cross-sectional pilot study which served two purposes. The first was to investigate the acceptability and feasibility of the proposed methods for re-creating mental images with this patient group, using a previously developed 'artistic' toolkit (Harrow et al, 2008). Furthermore this study would provide some preliminary data to inform the development of the larger, subsequent research study. Semi-structured interviews were carried out with a small sample of head and neck cancer patients, their partners, and relevant health professionals. The findings established that some patients, and indeed their partners, do generate a mental image of their cancer, and that such images tended to be realistic and enduring in nature, reflecting their perceptions of the cancer in terms of size and anatomical location for example. Images such as these were important in terms of both patients' and partners' overall understandings of the cancer, and facilitating understanding appeared to be their 'function'. Other reported dimensions of mental images were colour, shape, texture, and the perceived behaviour of the cancer. Those who did visualise the cancer were cognisant of the influences over their particular mental image, citing information from health professionals as especially important. Notably however, the clinicians who participated lacked awareness of these patients' mental images which seemed to be very much a private, hidden phenomenon. Visual concepts – images embedded in language – appeared to be significant in patients' conceptions of treatments also, and these impacted on how the cancer was visualised. This study also confirmed the acceptability of asking patients to re-produce their mental images, with all of those participants who reported having an image agreeing to re-create it.

10.2.3 EXPERIENCING HEAD AND NECK CANCER: A META-SYNTHESIS OF QUALITATIVE STUDIES

The findings from the pilot study and review of the literature demonstrated that a) for some patients the experience of HNC was inextricably linked to their mental images, and b) there is an apparent lack of qualitative work illuminating the broader experiences and perceptions of this patient group. Given the reputed dearth of evidence, and wide dissemination of (and thus difficulty in assembling) relevant studies across the literature, a systematic search for and synthesis of existing work was devised. Guided by Noblit & Hare's (1988) seminal method for integrating study findings, fifteen qualitative papers on the subject of the experience of head and neck cancer were scrutinised, and their findings collated and synthesised to produce a secondary interpretation of these original findings. This interpretation comprised six core themes. The context of head and neck cancer, the reality of living with cancer and enduring the treatments, was reflected in three themes – 'Living and waiting: Betwixt and between', 'Disruption to daily life', and 'The diminished self'. 'Living and waiting' embodied the prevailing uncertainty which characterised the experience of cancer, the interruption of life and unpredictability of the future. The reality of having cancer and in particular the impact of treatments was exemplified by the notion of physical, emotional, and social disruption where daily life is transformed and dominated by the disease – 'disruption to daily life'. The last of the contextual themes was the concept of 'the diminished self', and this referred to the functional, social, and existential losses experienced by patients due to the disruption caused by the cancer and treatments. Three further themes characterised how patients negotiated the experience and this was expressed as – 'Making sense of the experience', 'Sharing the burden', and 'Finding a path'. 'Making sense' reflected patients' continual efforts to comprehend their disease, by actively interpreting received information and constructing the meaning of their cancer, to form an understanding of what was happening to them. The final two themes, 'sharing the

burden' and 'finding a path' typify the need to develop a supportive connection with health professionals, and the view of the future beyond cancer – as simply changed by the experience, or as diminished by it – respectively.

10.2.4 HEAD AND NECK CANCER, IMAGES, AND EXPERIENCING TREATMENT

The pilot study of this project indicated that mental images played an important role in patients' understandings of their cancer and treatments, and the meta-synthesis provided further information about the experience of head and neck cancer. The final empirical phase of this project was a larger, longitudinal qualitative study which aimed to further explore the ways in which HNC patients understand and visualise their disease and treatments, the significance of this, and how this may evolve over the course of their experience. The scope of this study was purposely widened to include greater attention to treatment comprehension and visual concepts embedded in language as well as mental images of the cancer. Participants took part in two semi-structured interviews, one during the early stages of treatment, and the other some months following treatment completion. The findings of this larger study supported the pilot in terms of the responsiveness of patients' mental images of the cancer – how they evolved to reflect their changing understanding of the cancer in light of the perceived impact of treatments. The data from this study suggested that mental images of the cancer may exist on a continuum, being more implicit or explicit in nature, as a number of the participants did not explicitly acknowledge a mental image yet talked about their disease in terms which suggested an underlying implicit image of it. Patients' images of the cancer were functional and reflected patients' beliefs, and varied extensively in the degree of sophistication – from the most simple representations of what the cancer was to vivid, multi-dimensional mental images. Patients' understandings of their cancer and treatments appeared to be heavily embedded in both mental images of the cancer and other visual concepts – that is realistic or figurative images conveyed in language. Patients' images

of the cancer both could influence and were influenced by patients' beliefs about their disease, and thereby were capable of affecting their emotions. The significance of mental images and visual concepts embedded in language was in their facility as an explanatory tool in patients' minds, enabling them to formulate a comprehensive understanding of what was going on inside their bodies in terms of both the cancer and treatments. The complex and considered explanations offered by participants, the meticulous way in which information, and the ongoing status of their health (in terms of symptoms and treatment side effects), was interpreted and assimilated into their perceptions of the disease suggested that patients were continually striving to understand their situation, reflecting the theme of 'making sense' cited in the meta-synthesis. Both the cancer and treatments constituted 'uncharted territories' for these patients, and this lack of certainty pervaded the experience, which again mirrored the findings of the meta-synthesis ('living and waiting'). It appeared that mental images of the cancer and visual conceptions of treatments represented one facet of the individual's attempts to make sense of what was going on inside their body, and thus negate some of the uncertainty inherent to the experience by formulating a clear understanding of the cancer which enabled them to hypothesise about or predict the outcome. This finding will be further explicated in the main part of this chapter.

10.2.5 IN WHAT WAYS MAY HNC PATIENTS VISUALISE THEIR DISEASE?

The findings of both research studies indicate that many head and neck cancer patients do have a mental of what their cancer is which reflects elements of their understanding of it. The mental images generated by patients varied in sophistication, from the most basic implicit images which represented simple notions of physical form to explicit vivid, multi-dimensional mental images, the parameters of which may include colour, shape, size, texture and perceived behaviour. Mental images tended to be 'realistic' in terms of the individual's perception of anatomy, and could be either cellular-level

representations, holistic entity-type representations (such as 'tumour' for example), or a combination of the two where the cancer was perceived as a singular entity composed of cancer cells. The cancer was also characterised behaviourally as either a destructive force, attacking the body; or as a competing life force growing interminably. These behavioural aspects of patients' mental images were tentatively relatable to distinctions in age, high anxiety, and social engagement, and the potential implications of this are discussed further in this chapter. Specific illness beliefs concerning the perceived severity of the cancer and the likelihood of it 'spreading' were evident in patients' mental images, and as such these images had the power to reassure or increase patients' anxiety. Mental images of the cancer tended to be stable and enduring, but were responsive to new information – particularly the perceived impact of treatments, the understanding of which was heavily embedded in visual concepts.

10.3 CHAPTER OUTLINE

This chapter will first attempt to explicate the role of mental images and visual concepts in patients' understandings of their disease and treatments in the context of their experiences of being treated for cancer, keys aspects of which were the uncertain and unpredictable nature of the predicament, and patients' desire to comprehend their disease and treatments with view to predicting the outcome and therefore combating this sense of uncertainty. In this context the function of mental images and visual concepts – collectively referred to as 'visual knowledge' – can be characterised as enabling patients to find 'answers' to two fundamental questions – What is the cancer? and What is going to happen? The evolving nature of patients' understandings and mental images means that answering these questions is not a one-time affair but a continual endeavour involving the assimilation of new information into their existing mental images of the cancer. The origins and development or evolution of patients' mental images and

understandings will be outlined in the next part of the chapter, with particular reference to the apparent importance of information received from health professionals and discussion of the question of whether patients' beliefs precede their mental images, or the other way around.

Subsequently these findings will be discussed in relation to the primary theoretical basis for this project, Leventhal's self-regulation model (Leventhal, Meyer, & Nerenz, 1980). The congruence of aspects of the findings with this model will be described, and it will be proposed that patients' mental images and visual conceptions of treatments may comprise a sub-part of the cognitive response to illness, a kind of visual knowledge which interacts with patients' non-visual beliefs and also influences their emotional and behavioural response to it. The ways in which mental images and visual concepts are linked to the specific dimensions of illness representations (beliefs) posited by Leventhal will be considered, as will the concept of the 'coherence' of patients' understandings.

The chapter will go on to discuss the proposed distinction between mental images and visual conceptions embedded in language in terms of an implicit-explicit continuum of mental images and conceptual metaphor theory, reconsidering some key aspects of the debate in cognitive psychology about drawing inferences about internal mental representations. The latter part of this chapter will then present some of the methodological issues inherent to researching mental images . A core objective of this project was to establish a feasible method of accessing and externalising patients' mental images, and despite positive pilot results concerning patients' willingness to re-create their images this was not replicated in the larger study. Some possible explanations for this discrepancy, and the advantages and disadvantages of pictorial versus verbal representations of mental images of the cancer will be described . Issues pertinent to the potential impact of the research process upon the images reported by

participants, such as the question of whether the discussion of potential mental images may create them, and whether the communication of an internal mental image can influence it, will also be relayed. This chapter will close with reflection on some of the limitations of this project, and the potential implications of the findings for future research and practice.

10.4 CONTEXTUALISING PATIENTS' IMAGES

The raw data generated from the studies resonated to varying degrees with each of the findings from the metasynthesis, and it is intended that the qualitative findings with respect to patients' experiences be subsequently published elsewhere. Patients' mental images of their cancer embodied aspects of their understanding of both the disease and the nature of treatments, and their accounts of these images appeared to relate to two of the metasynthesis themes in particular – in terms of 'making sense of the experience', and the penetrating uncertainty of 'living and waiting'. There was support for both these themes in the broader context of patients' experiences, and the previous chapter described how the experience of cancer and the treatment process constituted 'uncharted territory' for patients, where the resolution of their illness is uncertain and the realities of undergoing treatment unknown. Unpredictability and anxiety characterised the experience in the recognised ability of the cancer to spread, persist beyond treatment, or recur in the future, and in the knowledge that the impact of treatments in terms of side effects and efficacy was highly individualised, and a successful outcome could not be guaranteed.

The descriptions of the cancer and treatments provided by study participants indicated that these patients did not negotiate the unfamiliarity and uncertainty of their situation unquestioningly. Instead they generally conveyed understandings of the cancer and

treatments which, while they varied in sophistication, often reflected complex and perhaps surprisingly realistic beliefs. Information imparted by health professionals was prized and, with the exception of a minority of patients who purposely avoided information as a way of coping, these patients actively sought to understand the nature of their disease and the treatment they would be undertaking (to a level they were comfortable with), and thus resolve some of the uncertainty and anxiety inherent to the situation. In essence, patients were striving to make sense of what was going on inside their bodies, and through this to predict what would happen in future in terms of outcome. The findings from the qualitative studies suggest that mental images may essentially be valuable as one facet of the mind's attempts to make sense of the situation – to understand what the cancer is, and what its implications are – and thus to counteract some of the uncertainty. It is in this context that patients' mental images of the cancer must be understood.

10.5 THE NATURE OF MENTAL IMAGES

Mental images of the cancer appeared to serve an important purpose in patients' broader understandings of their disease, representing and communicating information primarily with regard to two fundamental questions:

1. What is the cancer?
2. What is going to happen?

This section will describe the role of both mental images of the cancer and visual concepts of treatments in enabling patients to answer each of these questions in turn.

10.5.1 WHAT IS THE CANCER?

The generation of a mental image appeared to enable patients to commute their potentially abstract word-based diagnoses into a more tangible representation of 'the

problem', which appeared to enhance their comprehension of the disease. Mental images varied extensively in their nature and sophistication, and tended to be 'realistic' or literal in terms of constituting what the patient believed the cancer would look like, as opposed to figurative (non-literal) in nature. Essentially mental images of the cancer were first concerned with the physical identity of the disease.

Cancer is a much-publicised, euphemised, and socially mythologized disease (Sontag, 1978; Czechmeister, 1994; Clarke & Everest, 2006; Hanne & Hawkin, 2007), and patients were aware it takes a variety of forms. A diagnosis of cancer therefore can mean many things, and many patients cited examples of visual language or pictorial images used by HPs as a way of explaining their particular cancer. Such images appeared to commute a potentially abstract diagnosis into something more tangible and comprehensible – comprising either a cellular-level conception, a holistic entity-type representation (such as 'tumour' for example), or a combination of the two where the cancer was perceived as a singular entity composed of cancer cells. While the sophistication of patients' mental images varied extensively, from the most basic – and apparently implicit – images of a 'growth' or 'tumour' to multi-dimensional, detailed mental images of the cancer, having a mental image of it appeared to increase the coherence of patients' understandings of their disease regardless of how sophisticated this was.

There was an apparent readiness on the part of patients to accept and internalise the images they were exposed to, and this is delineated further in section 10.6 of this chapter which deals with the origins of mental images. This openness to external visual information which would provide a physical, visual identity for their disease suggests that a purely words-based representation of one's illness may be insufficient for some patients to fully understand their condition. This may be particularly applicable to

patients with head and neck or other cancers, given the social mythology of the disease, and certainly our data indicated that mental images of the cancer aided and increased comprehension.

The vast majority of the mental images related by our samples were stable and earnest in nature, not fanciful. Fears about the severity of the cancer and the likelihood of it spreading or persisting after treatment were embodied in the mental images of the cancer, as were beliefs about how it would affect the body – characterised as either a destructive force attacking the healthy structures of the body (destroyer) or a non-destructive life force which simply sought to prosper inside the body without attacking it per se. There was very limited use of figurative images to represent the cancer itself, and where figurative images were employed it was generally in terms of particular aspects (such as colour) of what were predominantly 'realistic' images. Elements of mental images of the cancer which were figurative in nature (relaying a non-literal meaning) tended to convey the patient's feelings about the disease, and participants were readily able to articulate the extent to which they felt these aspects were likely to be an accurate reflection of reality. The proposed facility of mental images of the cancer as a means by which patients interpret and make sense of their diagnosis is supported by the prevalence of factual or realistic mental images, and the intertwined relationship of these images and illness beliefs.

The primary function of mental images then appears to be to furnish the patient with a clear conception of what the cancer is – to enhance their understanding through the incorporation of a mental image – a kind of visual knowledge – into their words-based knowledge of the disease. Patients' beliefs and mental images thus appeared to have a two-way, interactive relationship, both reflecting and informing the other, and this interaction is discussed in the next part of this chapter which is concerned with the origins

of mental images. Images of the cancer seem to provide patients with a comprehensible identity for their illness, and this and the increased understanding which follows combats the potential ambiguity of the diagnosis and thus gives a measure of certainty.

10.5.2 WHAT IS GOING TO HAPPEN?

A second function of mental images was to facilitate an ongoing understanding of what was happening inside the body throughout the treatment process, and this was enabled by both the mental image of the cancer itself and visual conceptions of treatments. Congruent with the notion of negating uncertainty, patients appeared to be striving to 'keep track' of the status of their cancer and the progress of treatments in order to predict the likely outcome, and visual knowledge appeared to be central to this process. The previous section mentioned that patients' ideas about the potential consequences of the cancer, for example the risk of it spreading or its 'containability', were evident in their mental images of it, and this reflects one aspect of the question 'what is going to happen?' However, the main evidence for the proposal that patients' images are born of trying to combat uncertainty can be derived from the evolutionary nature of patients mental images, as new information – particularly the perceived impact of treatments – is incorporated into their mental image of the cancer.

For many patients, doubts about the efficacy of treatment were a source of significant anxiety. Even in those cases where the prognosis was good, fear of the possibility that treatment would not prove curative was evident. Patients were then in ongoing state of uncertainty, enduring a period of several months before they would learn of the outcome of treatment, and even then this was not necessarily regarded as definitive. Throughout this period of waiting, patients were continually searching for indications of the effectiveness of treatment, trying to predict the likely outcome and thus negate this aspect of uncertainty. Visual concepts of the purposes and nature of various treatments,

as patients understood them, were an important source of information as to the current status of their cancer and the achievements of treatment.

Visual conceptions of treatments primarily reflected beliefs in terms of the perceived 'action' or impact upon the cancer, and these kinds of images appeared to be important in terms of patients' understandings of treatments, particularly in respect of radiotherapy. Surgery and chemotherapy were relatively easily conceived of in terms of the physical removal of tissues, and the chemical 'killing off' or 'poisoning' of both cancer cells and 'good' cells. There was a far greater role for images in the form of visual concepts in patients' understandings of radiotherapy however, which in the absence of any tangible or observable impact during administration was assigned a visual identity by many patients, 'beams' or 'like a laser' for example. The majority view amongst the sample was that the radiotherapy acted by 'burning' away the cancer, and it was the mechanism of action about which patients' understandings were most embedded in visual concepts. The higher proliferation of visual concepts in relation to the most intangible/ incomprehensible of treatments, radiotherapy, does suggest that patients are striving to form a coherent understanding of the treatments they are undertaking, and that visual knowledge is an important facet of this. It is not the only possible explanation however. Radiotherapy is also arguably the type of treatment most associated with visual stimuli – x-rays, scans, and cross-sectional plans all employed in the very precise process of treatment planning, to which patients may be exposed. Such images are in effect images of the cancer, and thus it may be the case that radiotherapy is the treatment most conceived of in terms of visual concepts due to the greater application of clinical images, rather than in the absence of a perceptible identity and an easily comprehensible administration process.

The perceived impact of treatments appeared then to be applied to the existing mental image of the cancer, thereby providing a mechanism by which patients could mentally 'keep track' of the progress of what was happening inside their bodies. Other factors also influenced the envisioned progress of treatment upon the cancer – patients interpreting new information from clinicians, changes in their symptoms, and the side effects of chemo- or radio- therapy, as meaningful in terms of the treatment efficacy. Patients' apparent sensitivity to information of this kind, and the complexity of some of their interpretations of it, further indicates that understanding or predicting the likely progress and outcome of their cancer was important to many patients. Visual conceptions of treatments appeared to function as a way of comprehending it, and by interpreting the various impacts of radiotherapy and other treatments on the cancer, patients could form an impression of how successful (or not) it was being, and from there quell some of the uncertainty over the outcome.

10.5.3 IMAGES AND THE QUEST FOR CERTAINTY

From the findings of the qualitative studies reported in Chapters 5 and 9, it appears that patients generate mental images of their cancer as part of an ongoing quest for clarity about their disease, in the attempt to answer two fundamental questions concerning what the cancer is, and what the likely outcome of treatment might be. This hypothesis is supported by two of the key findings from the metasynthesis of patients' experiences of head and neck cancer – that patients strive to make sense of or understand their illness, and that the experience in its entirety is characterised by uncertainty – which were evident in the research studies also. The evolutionary nature of patients' mental images of the cancer, which were refined over time, suggests an ongoing search for certainty about their disease and its likely outcome (in the context of considerable uncertainty), in the following manner. The initial mental image of the cancer provides the patient with a baseline physical identity ('what is the cancer?'), and this visual knowledge in combination

with their non-visual (words-based) knowledge of the disease comprises their understanding of it (indeed the visual knowledge appears to enhance their overall comprehension). The subsequent modification of the mental image of the cancer then enables the patient to theorise about the progress of the cancer and treatments (i.e. 'what is it now? …and now?') in line with their perceptions of the impact of treatment, and to form ideas about the likely outcome ('what is going to happen?').

This section has proposed that mental images of the cancer play a crucial role in patients' evolving understandings of their condition. The following part of this chapter will reflect upon the origins and development of these images, and the question of whether patients' beliefs precede their mental images of the cancer, or vice versa.

10.6 THE ORIGINS AND DEVELOPMENT OF MENTAL IMAGES

Identifying the perceived origins of patients' images of the cancer was a key objective of this project, and the qualitative studies indicated three important influences: information from health professionals, the appearance and texture of the cancer (where this was discernable), and beliefs about the body and cancer. These three sources parallel to some extent those suggested by Leventhal as likely contributors to the formation of illness beliefs – 1) shared laypersons' information about the illness; 2) information from clinicians and other sources perceived as reputable, and friends and family; and 3) the physical experience of the illness and symptoms (Leventhal, Nerenz, & Steele (1984). This similarity between the sources of beliefs and mental images again reflects the intertwined nature of visual and non-visual knowledge. The 'accuracy' of patients' recollections notwithstanding, what was striking about the origins of patients' mental images was that all of those patients who acknowledged an image of the cancer (i.e. had an explicit image) were able to reflect upon and cite the influences they

believed were pertinent to how they visualised it. The sample groups for both studies constituted for the main part an open, articulate group with a good degree of self-awareness. In general they strove to understand rather than avoiding information about their cancer – reflective of the need to 'make sense' cited earlier in this chapter – and many were able to specify particular information they had received, and how they had interpreted it in terms of their mental image.

In their original study of breast cancer patients' mental images of their cancer, Harrow et al (2008) found that visual information – both verbal and pictorial – presented by clinicians appeared to be a powerful force in the development of patients' beliefs about their cancer and the mental images they generated. This exceeded the apparent influence of pre-existing beliefs over the images, and suggested that exposure to material images and images embedded in speech within a clinical setting were key factors in the creation of patients' understandings of their disease. The findings of both the pilot and larger studies undertaken within this PhD support this contention; with clinical images arguably the most important factor in how head and neck cancer patients visualised their cancer in the vast majority of cases. In the age of the internet where patients may have ready access to other – potentially conflicting – sources of visual and non-visual information about their cancer, it was perhaps surprising that clinical information retained its supremacy in terms of impact and perceived trustworthiness. However this echoes the findings of a recent analysis of the information-seeking behaviours of 252 people with a history of cancer which found that clinicians remain the most-trusted source of cancer information, even amongst those who sought cancer information online, and despite 60% citing the internet as their primary information source (Kim & Kwon, 2008).The impact of clinical images then may exceed that of visual information derived from other sources due to its perceived reliability.

Several cases cited in the preceding chapter demonstrated the potency of visual information imparted from health professionals in respect of patients' emotional well-being. The use of a simple sketch for example led Brian to feel his cancer was 'contained' and reassured him concerning the possibility of spreading and the efficacy of treatment. The converse effect was notable in Albert, who reported a HP's casual use of the word 'roots' as changing his mental image of the cancer from a self-contained, protruding 'growth' into something also setting down roots into his body, a concept which increased his anxiety about the likelihood of treatment success. Of course as with any self-reported data there can be no certainty about the accuracy of patients' accounts of the information they received from HPs. The relation of such information to patients' subsequent mental images could be investigated further through the audio or video recording of consultations (as was iterated at the end of Chapter 5), however this was not carried out as part of this study. The possible significance of clinical images on patients' understandings of and emotional responses to their cancer suggests that this may be an avenue worth pursuing. The apparent receptiveness of patients to 'new' information, and the responsiveness/alterability of their mental images, means such research may indicate ways in which verbal or pictorial images could be utilised purposefully within a clinical context to alter patients' beliefs and mental images and thus reduce patient anxiety.

It is important not to simplify the pathway to the cognitive generation of mental images however. Clinical images constituted one of three key influences over how patients visualised their cancer, alongside the patient's sense of the cancer– that is the appearance or texture of the cancer where this was detectable by patients, for example palpable lumps or the ability to see the cancer – and beliefs (and hence feelings) about the body and the nature of cancer. The dominant role of information provided by health professionals in shaping patients' illness beliefs and mental images of the cancer does

reflect the great trust placed in clinicians by patients, and the regarding of them as 'knowledgeable experts' from whom information was for the most part accepted without question. Whether these three perceptible sources represent the totality of the origins of patients' mental images of the cancer is indiscernible, and it is acknowledged that there may have been other more covert influences at work of which even the patients themselves were unaware.

Figure 13 - The origins of patients' beliefs and mental images of the cancer

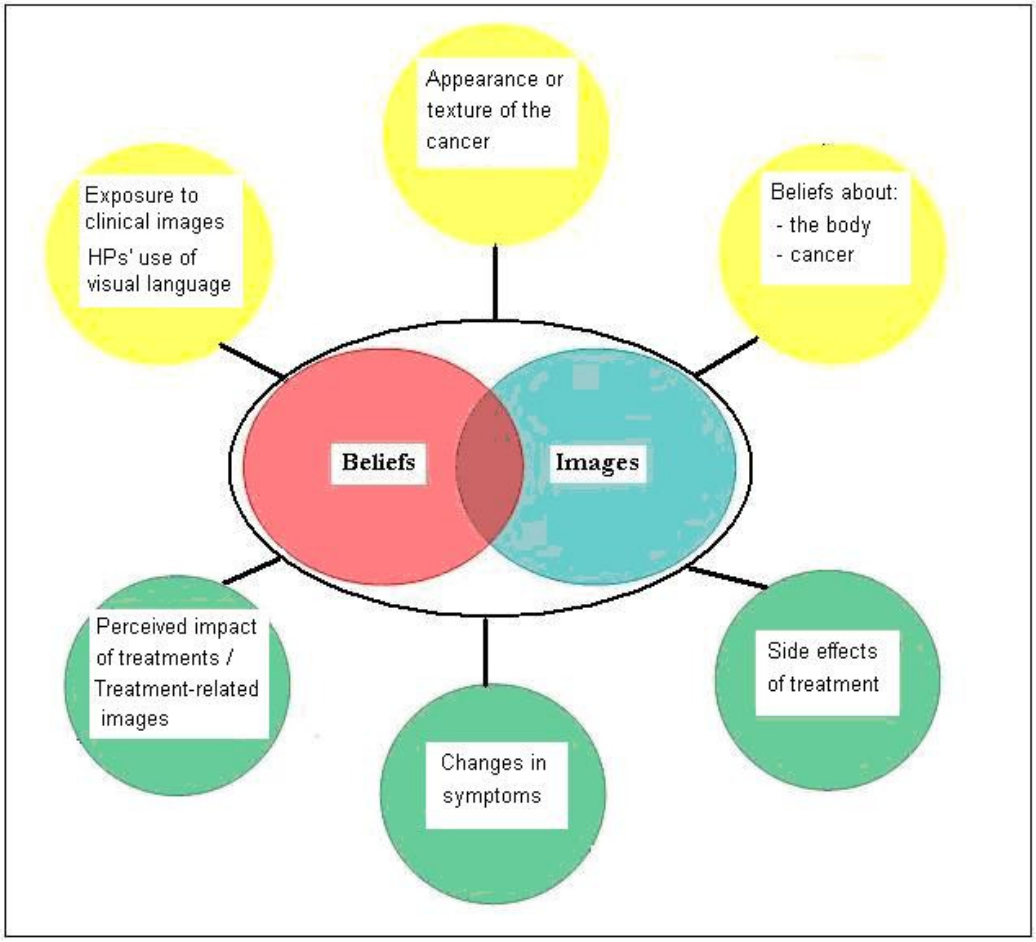


Figure 13 illustrates the perceived origins of patients' beliefs and mental images of cancer. Initially three key sources (shown in yellow) were identified: information from health professionals in the form of clinical images such as scans and the use of visual language, detectable symptoms – the appearance or texture of the cancer; and beliefs

about the body and the nature of cancer. These elements conspired to influence patients' visual and non-visual understandings of their illness, and there appeared to be a two-way relationship between illness beliefs and mental images. Over time three further sources of information (shown in green)– the perceived impact of treatments and visual concepts embedded in language which represented treatments, changes in symptoms, and the side effects of treatments – were interpreted and assimilated into patients' existing understandings, refining their beliefs and mental image of the cancer accordingly. Patients thus have an evolving knowledge, both verbal and visual, of their disease, and this supports the notion that patients are continually seeking to comprehend their situation, to formulate a coherent understanding of it.

10.6.1 DO IMAGES OR BELIEFS COME FIRST?

As the diagram above indicates, the findings of our studies suggest that illness beliefs and mental images have an interactive, bi-directional relationship, each informing the other. Our findings further echo those of Harrow et al (2008) in that it appears that predominately the beliefs and information from HPs came first and then informed the development of the mental image; but the reverse influence – mental images originating and then shaping patients' beliefs – was also evident. Indeed there were several cases within our sample illustrative of this reverse influence, where patients accepted an external image as representing their disease and then derived beliefs and expectations from there (for example Ashley, Brian, and Jean-Claude). The evolutionary nature of mental images further suggests that understanding could be moulded as a result of exposure to external images as well as creating mental images, and thus also supports the apparent bi-directional relationship between the two.

Without examining patients' mental images of cancer prior to and following exposure to external images, it is impossible to know definitively whether beliefs create the mental

image or the mental image creates beliefs. Such an endeavour would be ethically very difficult to carry out however, as clinical images are often presented to patients at the point of diagnosis as a way of explaining their disease. Assessment of pre-exposure mental images of cancer would therefore require interviewing potential cancer patients who may or may not have malignant disease during the typically highly stressful pre-diagnosis and diagnosis period (Poole, 1997; Ledeboer et al, 2005; Pineault, 2007). Furthermore pre-diagnosis mental images may reflect only generalised beliefs about cancer, rather than beliefs built on specific information about their particular cancer – information which according to our findings would likely alter any pre-existing mental images, and therefore research into such 'blind' pre-diagnosis mental images may be of questionable value anyway.

So far this chapter has proposed that head and neck cancer patients actively seek to understand their condition, and one manner in which they do this is by interpreting visual and non-visual information to generate a mental image of the cancer. It has been argued that such images complement patients' non-visual comprehensions of the disease, and the following section will relate the two further with reference to the underpinning theoretical basis of this thesis – Leventhal's concept of 'illness representations'.

10.7 PLACING PATIENTS MENTAL IMAGES IN THE CONTEXT OF THE SELF-REGULATION MODEL

Leventhal's self-regulation model (Leventhal, Meyer, & Nerenz, 1980), in particular the illness representations element, underpinned the development and design of this project, and is useful in explaining the possible 'place' of patients' mental images of cancer within their wider understandings of the disease. The enmeshed nature of mental images and HNC patients' illness and treatment beliefs suggests a close relationship between the

two. Visual information appeared to both influence and embody patients' beliefs – be it internally generated images such as mental images, or externally generated images such as clinical diagrams or x-rays. The reputed potency of visual information is well documented. Images may be more memorable than textual information, enhancing recall of news items (David, 1998), and health-related information (Houts et al, 2006), and may influence aspects of later accounts of news stories even without supporting textual information (Garry et al, 2007). Images have also been found to enhance the impact of health-promotion messages. For example the incorporation of warning images onto cigarette packets, has been found to increase intentions to quit smoking, beyond the impact of textual warnings alone (Kees et al, 2006). Internal, mental images of disease – the beliefs they embody, and how they are interpreted by patients – have been shown to powerfully affect patients' self-care behaviours and disease outcomes (Williams et al, 2007; Broadbent et al, 2004; Broadbent et al, 2006), as well as predicting the preventative behavioural intentions of healthy people (Cameron, 2008). If images are considered to be simply a second kind of information – which communicates certain messages to an individual as it is interpreted (consciously or unconsciously) – alongside non-visual information, then mental images could be regarded as a part of the cognitive response to illness described by Leventhal, integral to the development of the patient's 'illness representation'. The cognitive representation of the illness is purported to encompass a range of beliefs along five dimensions – the identity of the illness, perceived causes, anticipated consequences, timeline or predicted duration, and the potential to cure or control the condition (Leventhal, Meyer, & Nerenz, 1980). Figure 14, below, illustrates how mental images may be one facet of the individual's attempts to understand a diagnosis of cancer in line with Leventhal's theory.

Figure 14 - Incorporating images into the cognitive response to illness

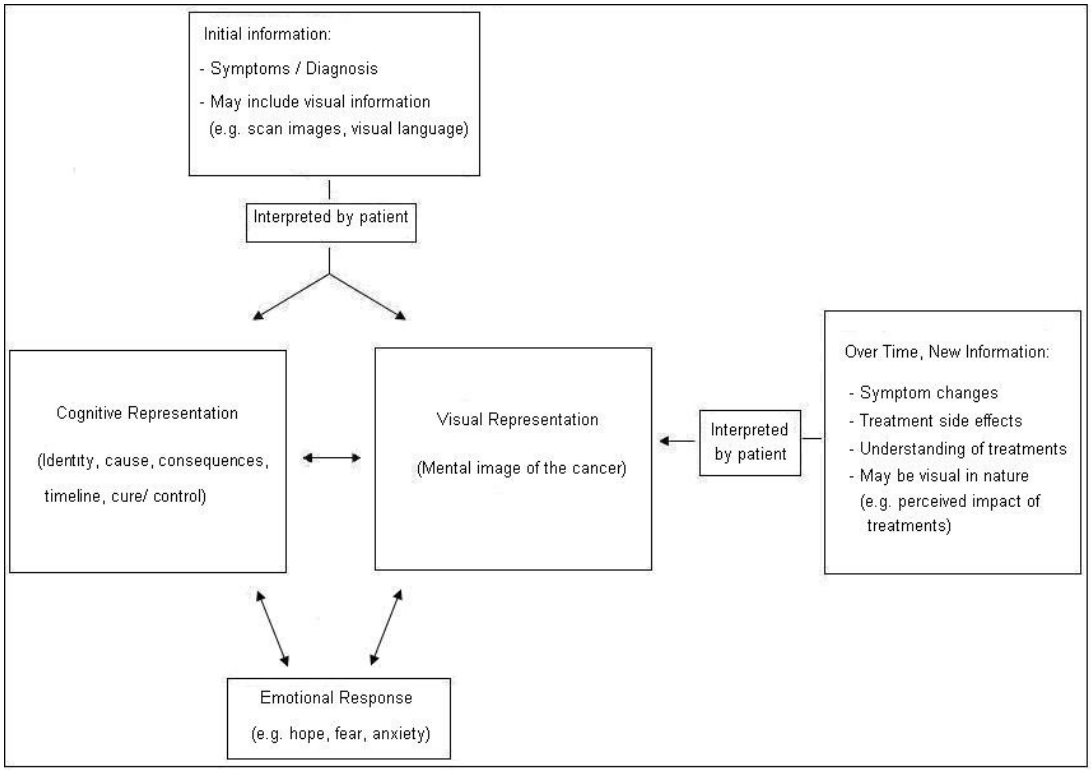


Figure 14 suggests that patients may generate a mental image of the cancer alongside the development of their illness representation (comprising cognitive and emotional representations), and that each of these elements feeds into and is affected by the other. Mental images of the cancer then are a part of the cognitive response to illness – both a source of information and the product of the interpretation of information. The findings of a recent study of perceptions of skin cancer risk have indicated an even wider role for images within cognitive representations of diseases, encompassing mental images not just of the disease itself but a range of associated images. Cameron (2008) studied the content of the skin cancer 'illness risk representations' of 120 healthy university students. Asking participants to list five images which 'immediately enter their minds' when thinking about skin cancer, images pertaining to a variety of topics were elicited, including symptoms (e.g. moles, blackened skin), treatment (e.g. scalpels, chemotherapy), and preventative behaviours (e.g. sunscreen, sun hat). The range of images represented beliefs about the illness identity, cause, consequences, and control; and the perceived

vividness of images, and images of symptoms combined with worry, predicted preventative behavioural intentions. Few other studies appear to have investigated illness-associated images within the illness representations framework other than realistic-type mental images of the disease itself. A notable exception is the work of Anderson & Spencer (2002) who elicited a range of metaphorical mental images from people with AIDS which reflected their perceptions of the consequences, causes, timeline, and controllability of the disease. Together the findings of these studies suggest that cognitive representations of illness may comprise numerous images pertaining to a range of beliefs, although the focus of this thesis was limited to mental images of the cancer and treatments.

As indicated in Figure 14, mental images of the cancer may directly influence the emotional response to illness, and vice versa, in addition to patients' non-visual beliefs. The apparent emotional power of images was outlined in Chapter 9, with mental images of the cancer capable of provoking anxiety or providing reassurance. Furthermore patients' emotions appeared to affect the mental images they reported, this was particularly evident in terms of those patients who expressed feelings of hopelessness and fatalism in their explanations of the assignation of the colour black to the cancer. The capacity of images to conjure up certain emotions is widely acknowledged. For example affective pictures are routinely employed in psychology studies investigating how the brain processes emotions, and related cognitive and physiological processes (Bradley et al, 2001; Olofsson et al, 2008). Images which are personal to the individual have also been shown to produce an emotional response, in contexts such as foetal ultrasound scans (Campbell et al, 1982; Harpel & Hertzog, 2010), and our findings are congruent with this research. The incorporation of new information into, and subsequent refinement of, patients' existing mental images of their cancer, demonstrates that patients' understandings of their illness are not necessarily static, patients re-evaluate

depending on how treatment is perceived to be progressing, and this then informs the further development of their beliefs and mental image.

10.7.1 HOW DO PATIENTS' IMAGES RELATE TO SPECIFIC BELIEFS?

In the terms of specific beliefs, the dimensions of physical identity, disease consequences, and cure/control were most salient in patients' mental images of the cancer. Mental images first and foremost reflected beliefs about the physical identity of the cancer – a cellular-based disease, a holistic entity, or a combination of the two. This kind of visual identity was important in terms of increased clarity about what the problem was, counteracting the potential ambiguity of a purely words-based understanding, and appeared to increase the coherence of patients' illness representations (outlined in the following section). The ability of images to improve comprehension in this way has been reported consistently in research testing the utility of including pictures in health information materials (Houts et al, 2006).

As described in the previous chapter, beliefs about the consequences of the cancer were reflected in patients' mental images in terms of its perceived severity – indicated in patients' minds by its size and anatomical location. Greater size suggested the cancer was longer established within the body and thus more serious. There was a prevailing belief that head and neck cancers were less serious than organ cancers due to the lesser proximity to other organs and perceived lower risk of spreading throughout these, though individual aspects of mental images such as its shape (i.e. the presence of 'roots') were also interpreted as indicating the likelihood of spreading, and knowledge of the surrounding tissues (such as the carotid artery) also influenced the anticipated consequences. More localised disease consequences were reflected in the cancer's characterisation as either a destructive force or rival life force, either attacking the healthy structures of the body or competing with them.

Beliefs about the potential cure or controllability of the cancer were also reflected in the perceived severity of the mental image and anticipated impact of treatments upon it (the evolution of the image). As illustrated in the diagram above (Figure 14), mental images – the 'visual representation' component of patients' illness representations – did impact upon their emotional response to the cancer through their interpretation of the likely consequences. In this way, mental images of the cancer were capable of evoking fear or providing reassurance, congruent with the self-regulation model.

10.7.2 WHAT ROLE DO IMAGES PLAY IN THE COHERENCE OF PATIENTS' UNDERSTANDINGS?

The primary function of mental images outlined in the first part of this chapter was to facilitate patient understanding with respect to two key questions – 'What is the cancer?' and 'What is going to happen?' It has been argued that visual knowledge in the form of images of the cancer and treatments may increase patients' comprehension of these. In terms of Leventhal's theory this is referred to as the 'coherence' of the patient's cognitive representation of their illness, that is the extent to which the patient feels they have a clear (coherent) understanding of their condition. Illness coherence was first identified as a dimension of illness representations by Moss-Morris et al (2002) who incorporated it into their revised version of the 'Illness Perceptions Questionnaire' (the IPQ-R). The degree to which patients feel their illness 'makes sense' has since been associated with a range of outcomes across a number of patient populations, for example high coherence related to better emotional well-being in post-treatment cancer patients (Traeger et al, 2009), and low coherence associated with the use of avoidant coping strategies in alopecia (Cartwright, Endean & Porter, 2009), and poorer functional status and quality of life amongst people with asthma, according to a recent review (Kaptein et al, 2010). Such findings suggest that improving patients' perceived comprehension of their condition

may be an important goal, and potential mechanism by which to improve psychological and functional outcomes.

While the construct of illness coherence was not assessed formally during this project, the proposed role of mental images as significant in patients' understandings of their cancer and apparent utility of clinical images in increasing comprehension indicates a potential future role for the purposeful use of material images of illness in achieving this aim. Recent research using such images in an explanatory way to increase coherence has demonstrated positive results in a number of areas, increasing perceived susceptibility to smoking-related diseases through presentation of ultrasound images of actual damage to the carotid artery (Shabab, Hall, & Marteau, 2007). Another recent study qualitatively assessed the impact of an animation demonstrating the relationship between obesity, the functioning and health of the heart and arteries, and related diseases, and reported increased perceived coherence amongst participants following the intervention (Williams et al, *In Press*). These findings suggest that both static and moving images may be useful in facilitating coherence of a range of conditions.

Further discussion of possible avenues for future research is contained in the penultimate section of this chapter (implications). The subsequent section considers the proposed distinction between mental images and visual conceptions embedded in language based on the findings of the longitudinal study in relation to debates about the form of cognition and how this may be determined emanating from cognitive psychology and cognitive linguistics.

10.8 DISTINGUISHING BETWEEN MENTAL IMAGES AND VISUAL CONCEPTS

The original focus of this thesis was on mental images as they were perceived by patients' to exist in their mind's eye (explicit images). Recognition of an internal mental image was therefore assumed to be a prerequisite of communicating it. However it was suggested in the previous chapter that patients' mental images of their cancer may exist on a continuum, being more explicit/conscious or implicit/unconscious in nature. Such a continuum may explain a number of cases where the participant appeared to convey a mental image of their cancer verbally throughout the discussion whilst simultaneously claiming not to perceive it visually. Accordingly, an implicit mental image is a conception or understanding of the cancer which refers to it as having a physical form which may be envisaged in the mind's eye, but is not explicitly acknowledged by the patient as an image.

The central difficulty in studying internal mental images is the lack of an objective way to measure this aspect of cognitive functioning. While numerous proximate indicators of internal visualisation have been proposed – such as the activation of areas in the brain involved in real visual perception– the validity of drawing inferences about internal mental images from such indicators is fiercely contested (as described previously in Chapter 3, section 3.7). Much of what we 'know' about internal mental images then is based on our own subjective experience. Schwitzgebel (2002) questions the usefulness of subjective accounts of internal mental images however, and points to the lack of a consistent relationship between self-reported experience of mental images and objective measures of mental images in the form of performance in cognitive tasks deemed to involve internal visualisation (such as mental rotation)[6] as indicating that individuals may

lack awareness of their own conscious (cognitive) experience with respect to internal visualisation, that it may be – to a greater or lesser extent – an implicit kind of cognitive process.

The notion of implicit or unconscious cognitive functioning is widely accepted, for example learning, knowledge, and memory are all considered to include both explicit and implicit aspects (Quinlan & Dyson, 2008). The existence of implicit mental images has been extensively studied in the context of motor activity, where current theory suggests that people 'mentally simulate' performing an action before actually doing so, i.e. they visualise it internally, and this process of mental simulation is both consciously and unconsciously executed (Jeanerod & Frak, 1999). In line with this perspective on cognitive functioning, it is proposed that mental images may exist on a continuum being more explicit or more implicit in nature. The data from the longitudinal study in which almost all patients appeared to conceive of their cancer with reference to an image of it embedded in language, yet a number did not identify this knowledge as constituting a mental image which was visualised in their mind's eye, is considered to support the notion of implicit mental images.

Images pertaining to treatments were also conveyed verbally. One interpretation of this would be that some patients also have implicit mental images of certain treatments in the same manner as verbally described – but not acknowledged – images of the cancer. However the apparent subtle differences in how treatments were represented via visual conceptions in language: through multiple, complementary images in a fragmented fashion (i.e distinct images to convey different perceived features of radiotherapy), in comparison to the verbal relaying of what appeared to be more discrete, clearly

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[6] Again empirical endeavours to elucidate internal mental images via cognitive tasks (another kind of proximate indicator) are open to fierce criticism - see for example Pylyshyn (2002)

defined and 'complete' singular images of the cancer; together with the fact that none of the participants described visualising the actual treatments as such – rather it was the perceived impact of the treatments as they pertained to the (explicit or implicit) mental image of the cancer (images relating to treatments acting in an ancillary or supporting role, and therefore dependent on the existence of an image of the cancer – that is they did not appear to be visualised as mental images in isolation); suggests that this explanation may be too simplistic. An alternative interpretation of what the prevalence these kinds of treatment-related images embedded in language in patients' accounts may suggest about how patients understand treatments can be derived from conceptual metaphor theory.

To consider this alternative interpretation a distinction is drawn between mental images of the cancer which exist in the mind's eye (be they explicit or implicit in nature), and a second kind of image – referred to as a visual concept/conception embedded in language which conveys a realistic or figurative image. Visual conceptions of treatments appear to be relevant/employed only as they relate to the underlying mental image of the cancer. Patients' understandings of the nature and purpose of radiotherapy, and to a lesser extent chemotherapy, appeared to be heavily embedded in this second kind of image, related through metaphor, simile and analogy. It is argued that the prevalence of visual concepts in patients' understandings of treatments reflects the important role of images in understanding abstract concepts, and that visual concepts of this kind are more conceptual that linguistic in nature – i.e. the description of radiotherapy as 'burning' is not merely a semantic choice but represents an underlying conceptualisation of radiotherapy. This is congruent with the view of linguistic expressions in the form of metaphors as manifestations of a system of thought by which people make sense of the world, known as 'conceptual metaphor theory' (CMT).

Building on earlier work (Lakoff & Johnson, 1980), Lakoff (1993) set out a contemporary theory of metaphor in which he argued that metaphors are part of the cognitive system through which concepts are understood (the conceptual system), not simply linguistic expressions, hence 'conceptual metaphors'. A metaphor is defined as a 'mapping' of a set of conceptual correspondences or features across a conceptual domain – from a source concept onto a target concept. Innumerable individual verbal expressions may be used to reflect an underlying conceptual metaphor, for example 'more is up' would be denoted by phrases such as 'the cost of petrol has risen' or 'share prices slumped'; while the metaphor – the mapping – is the concept of vertical orientation (risen or slumped) onto that of quantity (cost or price), and so the target concept of quantity (more) is understood in terms of the source concept of vertical orientation (up)[7]. Lakoff (1993; 2008) contends that a vast, highly organised system of fixed, conventional conceptual metaphors such as these is employed in the conceptual system, but that this system largely resides in the unconscious mind and its use is automatic (without conscious awareness).

Cited as "undoubtedly the most influential" modern theory on the form and function of metaphors (McGlone, 2007, p110), Lakoff's conceptual metaphor theory has had broad inter-disciplinary reach, influencing the study of metaphor in as diverse fields as computing, psychology, linguistics, and political science. In more recent years there has been significant theoretical debate and developments in reference to conceptual metaphor theory. For example authors have challenged the simplicity of single mapping

[7] It is important to note here that the interpretation of expressions such as 'share prices slumped' as having a meaning beyond the purely literal is fiercely contested. McGlone (2007, p123) has criticised what he terms Lakoff's "hyper-metaphoric construal of literal language" and the interpretation of seemingly literal statements as metaphorical at a deeper conceptual level. The term metaphor here is applied in the broadest sense of the word as per CMT in terms of the mapping of the features of one concept onto another, and is achieved via simile and analogy as well as actual metaphorical expressions

from a source to a target domain, suggesting rather more elaborate, integrated networks (Fauconnier & Turner, 2008); and have attempted to further delineate the cognitive processes underpinning metaphor use and understanding, such as the elucidation of comparison and categorisation processes involved in understanding simile and metaphor (Glucksberg, 2008); and to clarify the biological basis of conceptual metaphor thinking by investigating the activation of the neural networks of the brain (Lakoff's own updated version of CMT – the 'neural theory of metaphor', 2008).

Perhaps the greatest criticism of conceptual metaphor theory lies in the fact that the primary mode of research has been the investigation of linguistic expressions, and that these have been interpreted as manifest evidence of an underlying cognitive conceptual basis for metaphors. Relying on the examination of linguistic expressions to support the notion that metaphors are not merely linguistic expressions but reflect deeper conceptual thinking is, some authors argue, fundamentally flawed (McGlone, 2007; Casasanto, 2009). As Casasanto (2009, p127) explains:

> "…If Conceptual Metaphor is a theory of mental representation (and not just of language), then it must be true that people structure their abstract concepts metaphorically even when they're not using language. Yet, this claim is impossible to test with methods that require people to process abstract concepts in language."

Empirical support for CMT from studies using non-linguistic methods is inconsistent – for example Casasanta (2009) reports conflicting findings; while Katz & Law (2010) and Boot & Pecher (2010) cite findings in support of CMT, in particular the contention that conceptual metaphors are activated unconsciously and automatically and therefore reflect an underlying conceptual system rather than conscious linguistic associations.

The field of research into the function and meanings of metaphor, and how they are developed and understood, is vast, and a fuller discussion of it is not necessary for the purposes of this thesis which makes no claims about the nature of conceptual metaphors or broader conceptual systems. The interpretation of the thesis findings with respect to visual concepts embedded in language is limited to noting an apparent parallel between how visual concepts appear to function and the two central claims of conceptual metaphor theory:

1. That metaphor is a mechanism through which people can comprehend abstract concepts
2. That linguistic expressions may allude to underlying conceptual understandings (conceptual metaphors)

It has been posited earlier in this chapter (section 10.5) that images may serve to enhance patients' understandings of their cancer by translating potentially ambiguous, abstract information into a more tangible, concrete representation of it in the form of a mental image. The employment of visual concepts, particularly with regard to treatments, is considered to function in precisely the same way; enabling patients to understand more abstract, intangible concepts such as radiotherapy in terms of the features of more concrete concepts – congruent with the basic argument of CMT.

Distinguishing between different types of image that many figure in patients' psychological experience and understanding of their illness is difficult, and though some subtle distinctions in how the cancer and treatments may be visualised have been tentatively noted the qualitative methods employed in this thesis do not enable any more definitive conclusions to be drawn about the nature of cognitive representations in the form of images. What can be said however is that alongside mental images of the cancer – the original focus of the thesis – images also appear to play a role in how

treatments are understood – irrespective of whether such images constitute mental images in the same sense as those of the cancer, or are indicative of a conceptual system which employs images as a mechanism by which to comprehend abstract subject matter as per conceptual metaphor theory.

10.9 ACCESSING AND EXTERNALISING INTERNAL IMAGES

The findings of both research studies demonstrate that many head and neck cancer patients do formulate a mental image of their cancer, ranging from the most basic representations of physical identity to sophisticated, multi-dimensional mental images. The methodological approach to externalising patients' mental images was not consistently successful however. While all those who reported an image in the pilot study attempted to re-create it using arts materials, only eight participants in the larger follow-up study consented to do so – despite almost all patients describing an image of the cancer. The implicit nature of some mental images as outlined in the previous section, and the potential ambiguity in deciding what constituted an image of the cancer (described in Chapter 9, section 9.2.1.1) may explain much of this, but some other possible factors and methodological issues will now also be considered. The prevailing reticence to produce an image among the latter group occurred despite purposely employing the same manner in raising the subject of mental images in terms of both the kind of language used, and the timing – during the second half of the interview, allowing rapport and trust to be established first, an approach which has been employed successfully in eliciting drawings (Derry, 2002; Harrow et al, 2008). Yet there was not the same apparent reluctance to talk about the mental images, which patients generally described fluently, and this suggests that many patients – even during the anxiety-laden pre-treatment phase – may be willing to relate their mental images of the cancer verbally, but some retain a reluctance to produce a material image.

A number of issues appeared to inhibit willingness to communicate a mental image pictorially – anxiety over the impact of the process on oneself, doubts over the ability to re-create the image accurately, and some embarrassment. There were few cases where the notion of re-creating the image was clearly emotionally difficult, and only one patient openly demonstrated this, though she was unable to articulate the reasons why. The apparent power of images, the immediacy of their impact and their tangibility, is one possible reason for emotional reticence, perhaps fear that re-creating the cancer will 'make it real' – the affirmative power of visual information having been demonstrated in studies of the impact of foetal ultrasound images (Draper, 2001; Dykes & Stjernqvist, 2001). More commonly among our samples patients' reluctance appeared centred around their perceived inability to represent the image accurately through drawing due to either a lack of skill, not considering the particularly way in which they pictured the cancer to constitute an image of it, or the lack of acknowledgement of the image (holding an implicit image). Indeed a perceived lack of artistic skill has been identified as a chief factor in participants' reluctance to produce drawings in a research context in other studies (Kearney & Hyle, 2004). In terms of reticence due to difficulty in describing elements of the image, this was applicable primarily to those whose images contained a cellular element, as cancers cells themselves tended to lack a definitive form in patients' minds, and thus could not be re-produced (also the absence of a clear concept of this element of a broader image raised questions about what was meant by an 'image of the cancer'). Embarrassment over any kind of 'artistic' endeavour was also apparent, but while this may have been prohibitive in some cases, even those who did create an image related a feeling of embarrassment, yet were undeterred.

10.9.1 PICTORIAL VERSUS VERBAL REPRESENTATIONS

The majority of participants in the larger study externalised their mental images verbally, and this raised some questions about the methodological necessity of pictorial

representation. In the absence of drawing, patients provided vivid verbal descriptions of how they visualised their disease, and were still able to respond to specific questions and engage in extensive discussion of them. There did not appear to be a disadvantage in discerning the subjective meaning of aspects of the mental image to the patient, something which requires words to determine regardless of the production of an image. Furthermore, subjective meaning is not the only feature of mental images which cannot be conveyed pictorially – the stability, salience, and concreteness of the image for example; and other research has examined mental images related purely verbally in the absence of a pictorial reproduction (for example Anderson & Spencer (2002) whose sample of 58 AIDS patients produced only 8 drawings).

A drawback to the solely verbal representation of internal mental images however is that it does not facilitate objective analysis of individual aspects of the images, such as Broadbent et al's (2004) study of the percentage of damage drawn on depictions of the heart, though the objective analysis of images remains a contentious issue. Backett-Milburn & McKie (1999) have been critical of the prevalence of overtly quantitative content analysis of drawings elicited during qualitative research, the lack of consideration of contextual factors in image production, and the presumption that such images are direct and accurate projections of inner psychological and emotional states. The incorporation of participants' own explanations of the meaning of their drawings in the process of interpreting these appears to be increasingly advocated in qualitative work (Guillemin, 2004b; Driessnack 2006; Cross, Kabel & Lysck, 2006). The findings of Broadbent et al's (2004; 2006) quantitative examinations of patient drawings in relation to their illness beliefs are compelling however, and suggest that patients' beliefs, exhibited in their drawings, may be determined through objective analysis. However as the aim of this project was to examine the subjective meaning of patients' mental images,

the inability to analyse these in this manner due to the lack of re-production was not a relevant concern.

Purely verbal relation of mental images then appeared to be satisfactory in terms of the objectives of this research, yet there is one undeniable advantage in externalising mental images pictorially which justifies its preference methodologically: the negation of ambiguity. The problem with verbal descriptions is that words can convey different meanings to different people. The colour red for example may refer to a multitude of shades (pillar-box red, burgundy, scarlet, ruby), and the word 'big' refers to an unspecified scale which may be envisioned as a range of actual sizes – and without a visual approximation it is difficult to know how accurate the researcher's perception of the participant's mental image actually is. The lack of a pictorial representation may then compromise the researcher's understanding as they could imagine the described image quite differently to how the patient perceives it, and this may impede their ability to ask pertinent questions and thus interpret the meaning of the mental image correctly. That said, it could be argued that visual depictions are also open to multiple interpretations of meaning (Stephens, 1998, p66), hence the necessity for an accompanying verbal description.

Image re-creation can be limited in terms of materials and individual ability (Backett-Milburn & McKie, 1999), and how well pictorial methods can depict an image which exists in the mind's eye of the individual is difficult to determine. Produced images do enable the participant to comment on the accuracy of their drawing however, and this is more difficult when it is described verbally due to the potential ambiguities of language. Indeed patients were not reserved in their appraisal of the accuracy of their drawings, and where elements of the image could not be replicated (such as a particular colour) the pictures provided a baseline from where disparities could be relayed.

Methodologically speaking, externalising mental images pictorially was perhaps the most useful in terms of accuracy and facilitating discussion, but a verbal description was essential to be able to interpret these, and a solely verbal description of internalised mental images was not found to be intrinsically inadequate.

10.9.2 DO IMAGES EXIST IN THE MIND'S EYE PRE-INTERVIEW OR ARE THEY CREATED BY ASKING THE QUESTION OR BY THE ACT OF DRAWING?

This project attempted to answer basic questions concerning the existence and nature of mental images of the cancer amongst head and neck cancer patients. While almost all of the patient participants reported a mental image (though this appeared to be implicit in a number of cases), the extent to which these were naturally occurring and/or were changed through the asking of the question and the re-creation process is difficult to determine. Researchers doing observational research encapsulate this problem by cautioning 'that which is observed may be altered by virtue of its observation', in other words the knowledge that one is the object of study may produce modifications in participants' behaviour (Gray, 2009, p412). This is known as 'reactivity', and may be true of any phenomenon where the focus of study is revealed In this case the knowledge that the researcher is interested in mental images of cancer may alter participants' accounts, serve to create a mental image in the mind, or alter the reported meaning or importance attached to such images. While the participants in our two studies described their mental images as a 'real' part of their experience, certainly even the invitation to participate and the information handed out to patients could potentially be responsible for 'implanting' an image.

Some differences in the images reported in the pilot and larger studies may be relevant to this question. As the respective information sheets (see Appendices 1, 2 and 4) show, the pilot study was more strongly focussed on mental images of the cancer and methods

of externalising these, while the focus of the larger study was broadened to include images pertaining to treatments and to pay greater attention to visual concepts embedded in language and the role that this kind of image may play in their understandings of the disease and treatments. The greater emphasis on mental images in the pilot study information sheet may have been a factor in the increased willingness to reproduce these images amongst the pilot study participants. This emphasis could possibly have meant patients had time to (consciously or unconsciously) construct a mental image before or during the interview, whereas the broader scope of the larger study relayed to patients in the information sheets meant this focus was somewhat diluted. If indeed asking the question could 'create' an image in the mind's eye which was not otherwise occurring, then the strength by which mental images were proposed to patients in the two information sheets may explain the lesser re-creation of mental images in the second study.

Alternatively, the difference in levels of image re-creation between the two studies may have been influenced by the different stages of illness that patients in each study were experiencing. Levels of anxiety and distress have been found to vary throughout the experience of HNC, for example anxiety may be particularly acute immediately following diagnosis (Hutton & Williams, 2001; Ledeboer et al, 2005), and during the latter stages of radiotherapy (Sehlen et al, 2003). All but one of the pilot study participants were completely beyond treatment, and therefore perhaps this group had more emotional 'distance' from the cancer and were able to reflect upon it with less anxiety or distress, whereas the prospect of drawing out the cancer may have been more emotionally difficult for those still undergoing treatment. Certainly the majority of patients were not reticent to talk about mental images where they existed explicitly, even if there was some reluctance to re-create them. A further complication found in the latter study, was the notion of a cellular-level understanding of the cancer in which the

actual cancer cells lacked a specific form other than being 'different' to normal body cells. The formless nature of cancer cells in the minds of participants and the associated feeling of being unable to reproduce their conception of the cancer was not an issue during the pilot where entity-based images dominated. Perhaps the stage of trajectory was also relevant to this, for example clinicians' use of cellular terminology in explaining treatments was perhaps more pertinent in the minds of patients undergoing treatment, than in those for whom treatment was completed some time ago.

10.9.3 DOES THE ACT OF COMMUNICATION CREATE OR CHANGE THE IMAGE?

Harrow et al (2008) raised the question of how the act of reproducing an internal mental image may serve to create one rather than access a pre-existing mental image. I would argue however that the findings from this research suggest that mental images of the cancer may be naturally-occurring and not therefore simply generated through the raising of the topic of mental images or the re-creation process. The use of spontaneous visual language throughout the interviews prior to discussing whether patient had a mental image of their cancer was prolific, and in the longitudinal study it appeared that mental images may exist on an implicit as well as an explicit level. Additional factors which suggest patients' mental images were 'real' include the apparent 'concreteness' of these images and lack of embellishment given. For example, even when posed with questions about colour or texture, patients were quick to respond to these in the negative, and did not appear to develop their images further by the application of more characteristics during the course of verbal or pictorial communication, despite such characteristics being introduced into the conversation. The clarity amongst both samples of participants in accounts of when the mental image first occurred, the consciousness of the perceived origins of the image, and the proposed interactive, entwined relationship between patients' images and their broader understandings of the disease and treatments further indicate that mental images of the cancer may be a naturally

occurring phenomenon. It is certainly possible, however, that the process of talking about or re-creating the image may increase its concreteness in the mind of the patient by virtue of greater focus on the mental image. The proliferation of references to underlying mental images in conversation not specifically orientated to the topic of mental images however, and the argued implicit nature of some patients' images suggests that visual knowledge may operate and interact with patients' non-visual beliefs covertly.

Perhaps the only sure way to establish whether mental images of the cancer truly exist in the mind's eye pre-interview would be to examine patients' accounts of their experiences and understandings of their cancer for evidence of a mental image of it, without actually asking the question. There was very little evidence of such images found whilst scrutinising the studies pertinent to the experience of head and neck cancer for the metasynthesis. However the raw data presented in published papers is always limited, and this does not necessarily mean that indications of mental images or other visual conceptions pertaining to the cancer or treatments would be completely absent from these studies' entire datasets. The comprehension of the disease and treatments was further not the specific focus of the meta-synthesis papers, and our own findings suggest that mental images appear to be a relatively hidden phenomenon, patients reporting not discussing how they visualised the cancer with anyone. It may be that mental images of the cancer are not simply created by the asking of the question, but only up until recently not considered important, and thus largely absent from existing accounts which lack a specific focus on images.

As illustrated by the preceding sections, accessing and externalising internal mental images of the cancer is not necessarily straightforward. Pictorial representation of mental images is dependent first on the image being explicit – acknowledged by the

patient – as opposed to implicit in nature, and on the patient's subjective assessment of whether their image constitutes an 'image of the cancer' and therefore the perceived applicability of a request to re-create it. Further to this patients may be reluctant to re-create their mental images due to a sense of embarrassment, a perceived inability to do so accurately, or concerns about the potential emotional impact of depicting the cancer pictorially. However our findings suggest that a verbal account of internal mental images may be sufficient in these cases, and given the potential power of images and their capacity to impact on patients emotionally, it is right to respect reticence to produce a material image when this is apparent. Another issue complicating research into mental images is the degree to which the study information, the actions of the researcher, and the process of communicating the image may create or influence mental images unbeknownst to the participant, and this is impossible to assess and an obvious limitation of this study. The final part of this chapter will recount some of the other limitations, and then detail the implications of the study's findings in terms of future research and their relevance to clinical practice.

10.10 THESIS LIMITATIONS

There are several limitations to this study, a number of which have already been delineated in this chapter. The qualitative nature of the research means that the findings of all three empirical components of the study are a reflection of the researcher's own interpretation, and it is likely that were another researcher to analyse the study data they would produce a slightly different set of findings. Furthermore, due to the influence of the researcher in the generation of qualitative data – data is the product of the interaction between researcher and participant (Potter & Hepburn, 2005) – a different researcher enacting data collection may also generate different study data. The findings of the two research studies reported here are peculiar to the experiences of a small

sample of patients from the North-East of Scotland, and are contextually-bound and so will not necessarily apply to the broader head and neck cancer population, and do not reflect potential differences in clinical and mental images in other cultures.

Indeed the demographic profile of the project samples may also be a limiting factor. As was intimated in Chapter 7, there was a predominance of younger, more affluent/educated participants, who did not smoke or drink heavily, and who are generally untypical of the 'traditional' HNC population, to whom these findings may be less applicable. The availability of younger, non-smoking, moderate-drinking patients does however reflect the evolving demographic of particular head and neck cancers, with increasing numbers of oropharyngeal cancers now attributable to a distinct viral aetiology (the human papilloma virus or HPV) (Westra, 2009). The purpose of qualitative research is not to produce generalisable findings representative of a patient population however, so while these issues are important to note, in the context of a sampling strategy seeking a range of patients from a variety of backgrounds the lack of representativeness in the traditional sense is not considered a limitation of the same import as it would be in quantitative studies.

Specific methodological limitations concern the timing of accessing study participants. The pilot study findings were limited by the retrospective nature of patients' accounts of their experiences (up to eleven years post-treatment), as subsequent events can colour recollections of what occurred, and was thought and felt at different times (Entwistle, Tritter, & Calnan, 2002). Similarly, while the larger study was longitudinal – interviews during the early/pre-treatment stage and following completion of treatment – in terms of the evolution of mental images, patients' accounts were somewhat retrospective. The lack of substantial differences in the understandings of the cancer and treatments shared at interviews one and two indicates a degree of consistency in patients' beliefs across

this period, something which could not have been ascertained from single interviews. However the apparent responsiveness of patients' mental images of the cancer to new information, to patients' evolving understandings of the impact of treatments on the body, could only be relayed in a retrospective fashion once treatment was completed. A preferable way of examining this would have been to include at least one interview during the treatment period, closer to the time at which changes in symptoms and treatment side effects first occurred and were perceived to influence how patients visualised their cancer. The realities of undergoing treatment for head and neck cancer however – the extensive functional impairments and accumulation of side effects that can be imposed by surgery, radiotherapy, and chemotherapy – mean that a mid-treatment interview would be at best an additional burden upon patients during a difficult time, in many cases impractical due to the potential physical state of patients at such a time, and at worst entirely unethical. Therefore retrospective study of the development or evolution of patients' understandings of what was going on inside their bodies and their mental images was the only feasible option, and while this is a limitation, patients were able to give remarkably clear accounts of the perceived reasons for changes in their mental image of the cancer which appeared consistent with their broader understandings of the cancer and treatments.

A further limitation of the proposal that mental images and visual concepts embedded in language are important in enhancing the coherence of patients' understandings of their disease is that, although this appears to be the case, this construct as defined by Moss-Morris et al (2002) was not assessed formally. Administration of the revised version of the Illness Perceptions Questionnaire (IPQ-R) would have provided a measure of the degree to which patients felt they understood their cancer, which could then be related to the salience of mental images and other visual concepts (of lack thereof) in their illness and treatment beliefs. Such a measure could also identify whether certain types of

images facilitate increased illness coherence over others, which may have implications for the communication of verbal and material images in a clinical context. At this moment, though mental images and visual concepts embedded in language appear to be important in terms of patients' comprehension of what the cancer is, its potential consequences, and the purpose and nature of treatments, the comparative usefulness of difference kinds of images, and the extent to which these may increase coherence has not been established in any definitive manner.

Finally, this chapter has reported on the place of mental images within the broader context of the experience of head and neck cancer; an experience characterised by a lack of certainty and, for the majority of patients, a desire to make sense of what was happening to them. These contextual elements were reflected independently in the qualitative data from the studies, but also comprised two of the thematic findings from the metasynthesis. The order in which the empirical components of this project were undertaken therefore becomes important. The process of carrying out the meta-synthesis undoubtedly influenced the researcher's approach to the subsequent study data – attracting attention to that which appeared to reinforce or refute those findings – and this may be considered both a strength and weakness of this project. The difficulty with this kind of prior experience is that it may colour the researcher's perspective to such an extent that she begins imposing pre-existing categories onto the data rather than deriving the findings from it. Indeed the consistency of the findings from both endeavours may be interpreted as evidence of this. However such consistency may also be an indication of the 'truth' – in the experiential rather than objective sense – of these elements in the experiences of head and neck cancer patients. This contention is supported by the reflection of these findings in other published research, numerous studies reporting pervading uncertainty as inherent to experiences of cancer (for example Shaha et al, 2008; Harrow et al, 2008b; Semple et al al, 2008), and

indicating the need of patients to feel they have sufficient information to understand – or make sense of – their cancer and treatments, to the extent that they desire (such as Ziegler et al, 2004; Llewellyn, McGurk & Weinman, 2006). The importance of these elements is emphasised in the studies cited above, in which both uncertainty and inadequate perceived information (detrimental to patients' abilities to make sense of their experiences) have been associated with poorer psychological functioning.

10.11 IMPLICATIONS FOR RESEARCH AND PRACTICE

Mental images of the cancer appear to be a hitherto hidden aspect of head and neck cancer patients' experiences. A secondary objective in carrying out the meta-synthesis was to scrutinise the published raw data in the qualitative studies for any references to images of the cancer, such allusions were however, conspicuously, largely absent. Though this says little about the existence of mental images itself (which was by no means a focus of the studies), it perhaps emphasises what appears to be the hidden nature of patients' mental images. Pilot interviews with health professionals working with this patient group suggested little awareness that patients may visualise their cancer, and the participants in both studies reported never discussing their mental images with anyone. The possible existence of mental images of the cancer is not the only aspect of patients' experiences about which clinicians may lack awareness, for example Wells (1998) reported considerable reluctance among HNC patients experiencing significant functional difficulties to disclose these to clinicians during follow-up. Explication of those hidden aspects of experience through in-depth qualitative work with HNC patients is an important direction for future research.

The findings of this project, together with those of Harrow et al (2008), indicate that how clinicians communicate with patients, especially their use of visual language and clinical

images – plays an important role in how patients understand and visualise their disease and treatments. The potency of images of the cancer in terms of reassuring or increasing the anxiety of patients means that clinicians may potentially impart 'harmful' messages to patients in the course of routinely explaining their disease/treatments (Williams & Cameron, 2009). The apparent link between exposure to verbal and material images in a clinical setting and subsequent beliefs about and mental images of the cancer could be investigated through a larger trial combining audio-recording of consultations with assessment of patients' illness beliefs and mental images. The incorporation of measures of anxiety would also allow the exploration of how particular beliefs or characteristics of mental images – such as the cancer's perceived 'containability' – may relate to the amount of distress experienced.

Explication of especially distressing features of mental images, and potentially of other images of the cancer that patients may be exposed to (such as scan images), would then provide the basis for an image-based intervention. The responsive nature of the mental images reported by participants in the two research studies, coupled with the greater significance apportioned by patients to information received from health professionals, suggests that clinicians may be well-placed to implement such an intervention. Furthermore the receptiveness of patients to new information, and the application of this information to alter existing mental images of the cancer indicates that patients' mental images are potentially changeable, and it may indeed be possible to 'implant' more positive or less distressing mental images as a way of reducing anxiety. Morgan, Roberts, & Stahlschmidt (2008) reported just such an effect in their exploratory study involving showing young cancer patients (13-24years) slides of their cancerous tissues with the aim of enhancing communication with clinicians, understanding, and involvement in decision-making. Exposure to these slides of their own cancer appeared to remarkably alter patients' existing mental images of the cancer, as they describe:

> "… A change in the patient's images of their cancers from being 'big, black, evil, destructive, painful or alien' to that of 'insignificant jelly beans' and 'tiny sausages.' … One young man, who had previously felt that he was controlled by aliens, saw his leukaemia as 'a strange planet' which no longer controlled him." (Morgan, Roberts & Stahlschmidt, 2008, p1483)

These findings reinforce the potential for clinical images to be utilised to promote positive outcomes. At the very least the identification of potentially 'harmful' messages communicated via particular images would be valuable in informing the ways in which information is conveyed to patients, as the increasing use of images in clinical communication is as yet implemented on an 'ad hoc' basis, without clinicians necessarily being cognisant of the adverse potential of such images (Williams & Cameron, 2009). Subsequent training in clinical communication could convey the potential potency of verbal and material images in communication, alongside increasing health professionals' awareness that patients may generate a mental image of their cancer – that is a visual representation of it in addition to their non-visual, words-based comprehension of it

The tentative disparity in levels of anxiety and social isolation noted between those patients who visualised their cancer as a destructive ('destroyer') force and those who perceived it as a rival, non-corrosive life force, is one potentially exciting area for future research . As intimated in the previous chapter, this apparent pattern in the data is proposed only in the most tentative terms as neither anxiety nor social isolation was assessed formally. These categorisations of participants were instead made on the basis of the qualitative data, including the researcher's field notes, and therefore reflect her subjective impressions of participants in these respects. In the absence of a more reliable measure, only those patients who were considered to be clearly definable as being at one of the more extreme ends of the anxious-unconcerned and isolated-socially

engaged continuums were categorised as such. Therefore approximately only two-thirds of the sample was classified, the other participants not exhibiting with sufficient strength indications of their level of distress or social engagement to enable the researcher to interpret this confidently. Nevertheless this seeming distinction between the two groups is interesting, particularly as no other demographic or disease factors (such as gender, location of cancer, or modes of treatment) appeared significant to any of the other differences in patients' beliefs about and mental images of the cancer.

Whether characterising the cancer as destructive as opposed to simply 'growing' has any meaningful relationship with the anxiety experienced – causatively or as a reflection of anxiety – cannot be determined through the methods utilised for this project. Nor could the possible relationship between 'destroyer' type images of the cancer and social isolation be established. However a larger study may use quantitative measures of anxiety and loneliness alongside qualitative explication of how patients visualise their cancer to investigate whether a relationship between these factors does exist. Anxiety and social isolation are pertinent issues with respect to head and neck cancer patients. This population has high rates of psychiatric morbidity, and isolation and loneliness may also be more prevalent amongst this group (Rozniatowski et al, 2005; Wells & Kelly, 2008). Social isolation, when assessed in terms of marital/cohabitation status and a lack of social support has been related to depression (Haisfield-Wolfe et al, 2009), and poorer health-related quality of life post-HNC (Woolley et al, 2006; Karnell et al, 2007). Living alone has even been linked to poorer survival amongst male patients (Konski et al, 2006). Therefore research with HNC patients which may lead to methods for identifying patients who are highly anxious or socially isolated, or methods to counteract such anxiety, would be valuable. Additionally if such a relationship was established the conveyance of clinical information which may inadvertently support the destructive characterisation of cancer would be one area for application.

Employing patient drawings as a method of accessing patients' illness beliefs via their mental images of the cancer was not wholly successful throughout this project, as many of the participants in the longitudinal study declined to re-create their mental images for reasons already outlined in this chapter. However the verbal externalisation of mental images also enabled in-depth discussion of these and pictorial representation is therefore not necessarily fundamental to research into mental images, though it does have a number of advantages. Ultimately where the aim is to understand the subjective meaning of mental images greater importance may lie in eliciting what these images represent to the individual, rather than a material re-creation of it. Relating internal mental images whether verbally or pictorially may also be a valuable means of facilitating conversation about the patient's fears, and this may be a particularly worthwhile endeavour with HNC patients given the high prevalence of fears of recurrence post-treatment (Humphris & Ozakinci, 2006; Rogers et al, 2010). The fact that the mental images relayed in this study were pertinent to the perceived consequences of the disease (in terms of severity and treatment success) suggests that exploring mental images of the cancer may be a particularly useful method through which to elicit recurrence fears. In a small number of cases discussion of how the cancer was visualised led to the disclosure of other emotions and fears not otherwise revealed, and the facilitative power of visual methods in eliciting emotions has been noted elsewhere (Kearney & Hyle, 2004). For example the importance of the perceived 'containment' of the cancer in reducing Brian's anxiety about treatment efficacy, and Nell's fear that her incurable neck cancer would culminate in her choking to death, were not elicited though other pertinent conversation, and thus the relation of mental images of the cancer may provide an additional medium through which specific concerns can be expressed. This is supported by studies which have investigated the usefulness of visual means of communicating patient concerns to clinicians, for example photographs of

relevant daily behaviours enabling the articulation of issues around the self-management of diabetes (Smith et al, 2006).

The importance of understanding patients' visual and non-visual representations of their illness is emphasised by the intertwined nature of beliefs and mental images and the ways in which patients appear to build expectations of outcome (particularly in terms of treatments) based on these interpretations of what is going on inside their bodies. Clinician and patient perceptions of disease often differ, for example clinicians have been found to underestimate the severity of functional difficulties such as dry mouth, dysphagia, and hoarseness, in post-radiotherapy and post-surgery HNC patients, compared to the patient's own perspective (Jensen, Jensen, & Grau, 2006). Patients' preferences in terms of functional outcomes may vary widely and health professionals' perceptions of patients' priorities may not be accurate (List et al, 2000.) HNC patients may also harbour unrealistic expectations as to the outcomes of treatment and recovery process (Llewellyn, McGurk & Weinman, 2005). Divergence in clinician and patient perceptions of the disease and treatments can therefore be problematic, potentially compromising effective follow-up treatment for side effects, satisfactory treatment decision-making, and patient psychological well-being. Clinicians may not be aware of patients' expectations of disease and treatments, and discussion of how the patient may perceive the cancer in terms of a mental image may enable the clinician to better understand patients' illness beliefs and any specific expectations reflected in their image of it, providing an opportunity for intervention and management of these expectations in line with what is realistic. This may increase the patient's overall satisfaction with care (Ziegler et al, 2004; Llewellyn, McGurk, & Weinman, 2006; Winterling et al, 2009), as well as fostering a good clinician-patient relationship.

The findings of the meta-synthesis provide further insight into some of the difficulties faced by head and neck cancer patients – the struggle with uncertainty, the gravity of the impact of treatments and the extensive disruption to life which results, the losses of functional, social, and existential kinds, and the importance of the relationship with health professionals. Clinicians' beliefs about what is important to patients in terms of the impact of cancer on their broader lives may be incongruous with those of the patients themselves. For example patients may be willing to accept the greater levels of toxicity and functional impairments imposed by more aggressive treatments in order to survive (List et al, 2004), and may rate the most significant infringements on quality of life differently to clinicians (Mohide et al, 1992). These disparities are important as clinician perceptions of patient quality of life influence treatment decision-making (Demez & Moreau, 2009). Relevant qualitative research such as the meta-synthesis may enhance clinicians' understanding of how both cancer and the treatments are experienced, and draw attention to some of the specific issues encountered by head and neck cancer patients, with whom research of this kind is still comparatively lacking, despite the recent proliferation of qualitative studies with HNC patients in the literature. Further qualitative work could include the partners or carers of HNC patients, whose experiences have thus far been largely neglected despite evidence from quantitative studies showing that the partners of patients with HNC and other kinds of cancer may too experience considerable distress (Pitceathly & Maguire, 2003; Hodges, Humphris & Macfarlane, 2005; Verdonck-de Leeuw et al, 2007; Ross et al, 2010). Such research could focus on the identification of unmet needs with a view to developing helpful practical or psychological strategies to mediate some of the difficulties in living with head and neck cancer

10.12 CONCLUDING REMARKS

This thesis has proposed that both internal mental images of the cancer as well as other images in the form of visual conceptions embedded in language, appear to be significant in terms of head and neck cancer patients' understandings of their disease and treatments. It has suggested that such images function primarily as a way of enabling patients to form a coherent understanding of their experience, with particular regard to what the cancer is (its physical identity), and what is likely to happen (the consequences of the cancer and outcome of treatments). Participants in this research appeared to be striving to comprehend their experiences, seeking to allay the uncertainty pervasive to their situation by generating theories about how the cancer and treatments were progressing, and visual knowledge was integral to this process, reflected in the evolving nature of patients' mental images of the cancer.

The findings of this thesis indicate that exploring patients' mental images of their disease may be a viable method of accessing their illness beliefs, as images and specific beliefs concerning the nature, severity, and consequences of the cancer appeared to influence and interact with each other. The ways in which verbal and material images were used in a clinical context strongly influenced patients' interpretations, and greater attention to this could be important, as it may be possible to manipulate patients' mental images and understandings of their cancer to promote better psychological outcomes. Most pertinently these findings support those of a small but growing field of research which submits that patients' understandings of their disease may comprise a visual component in the form of a mental image as well as the more traditionally acknowledged non-visual, words-based component, and that to fully appreciate their experiences we ignore the former at our peril.

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Appendix 1: Pilot study patient information sheet

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer Patients' Beliefs and Images: Pilot Study

PARTICIPANT INFORMATION SHEET – FOR PATIENTS

You are being invited to take part in a research study. Before you decide whether or not you'd like to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. If there is anything which is unclear, or if you would like more information, please feel free to ask the researcher. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study involves talking to people who have been diagnosed with cancer of the head and neck, their partners, and relevant health care professionals, about different aspects of their experience of this illness. Some other studies involving patients with other illnesses have shown that the mental images that patients have of their illness can embody their beliefs and feelings about their illness. This study aims to look at the different ways that head and neck cancer patients may picture or imagine their cancer, from where these images originate and how they develop, the best ways of re-creating these images, and how mental images link to beliefs and feelings about the illness.

Why have I been invited to participate?

You have been invited to participate because you have been diagnosed with head and neck cancer, and we wish to learn about your experience of this illness and how you may have pictured it in your mind. A total of approximately 12 people – 6 patients, 2 partners, and 4 health care professionals – are needed to participate in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Today, the researcher will ask you for a contact number and arrange a time to call you to ask if you would like to participate. If you choose not to participate you will not be contacted again. If you do wish to take part, you will be asked for a date when for the researcher can meet up with you. This could take place within you own home or in a private area in one of the hospital or University departments. You can withdraw from the study at any time and do not have to give a reason. Choosing not to take part, or choosing to withdraw from the study, will not affect the standard of care you receive in any way.

What will happen to me if I take part?

If you choose to take part you will be asked to take part in an informal interview. Your travel expenses will be reimbursed if you choose to have the interview away from your home. The interview will be conducted by the researcher you met with today, and will probably last for about 40 minutes. You will be asked about your experiences, how you think about your cancer, and whether you have a picture of it in your mind. You will be then be asked to describe and/or recreate any mental images you have using pens, pencils, or other materials – whichever method you find most helpful. If you do decide to recreate your images, the interviewer will ask you to describe what you are doing and what the images mean as you recreate them. If you agree the researcher will video you creating the images- your face will not be shown - and also tape-record what you say. However, these recordings will be treated confidentially and no-one other than the research team will know what you said or who you are. Any information which identifies you specifically will only be known to the research team. You are free to stop the interview at any time.

Audio recordings will be stored securely for up to three years and then destroyed. Video recordings will be stored indefinitely, but your face will not be recorded and these videos will also be stored in secured, locked drawers.

When writing up the results of this study, some direct quotes and some video images may be used, but these will always be anonymised – you will be given a false name and no identifiable information about you shall appear anywhere in the report.

The Tayside Research Ethics Committee have examined this project and approved it. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside.

How will the information I give be used?

The information you give us will help us to understand more about what head and neck cancer means to those who have it, and how people picture it. The results of this study will help us to understand how patients' mental images of their illness can affect them, and perhaps suggest some ways we could help people to explore their beliefs about their illness through these images.

The information you give us will be collated with the interviews with other participants, to help us understand the different experiences of head and neck cancer. When the study is completed, the results of the study will be written up, presented to the funding body and the researcher's supervisors at the University of Dundee, and may be published in academic journals. If you would like, a copy of the results can be sent to you, and you can contact the researcher if you have any questions or wish to discuss your participation further.

Who is funding this study?

The study is funded by the Chief Scientist Office. It is part of a PhD Studentship being undertaken by the researcher.

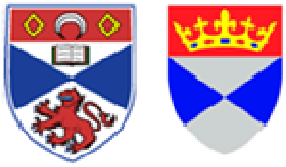
How can I get more information or contact you?

The researcher can be contacted by letter, telephone, or email.

Heidi Lang
Social Dimensions of Health Institute,
11 Airlie Place,
Dundee,
DD1 4HJ.
Telephone: 01382 386664
Email: hvlang@dundee.ac.uk

Thank you for taking the time to read this Information Sheet and considering taking part in this study.

Appendix 2: Pilot study partners information sheet



Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer Patients' Beliefs and Images: Pilot Study
PARTICIPANT INFORMATION SHEET – FOR PARTNERS

You are being invited to take part in a research study. Before you decide whether or not you'd like to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. If there is anything which is unclear, or if you would like more information, please feel free to ask the researcher. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study involves talking to people who have been diagnosed with cancer of the head and neck, their partners, and relevant health care professionals, about different aspects of their experience of this illness. Some other studies involving patients with other illnesses have shown that the mental images that patients have of their illness can embody their beliefs and feelings about their illness. This study aims to look at the different ways that head and neck cancer patients may picture or imagine their cancer, from where these images originate and how they develop, the best ways of re-creating these images, and how mental images link to beliefs and feelings about the illness.

Why have I been invited to participate?

You have been invited to participate because you are the partner of someone who has been diagnosed with head and neck cancer, and we wish to learn about your experience of this illness and how you may have pictured it in your mind. A total of approximately 12 people – 6 patients, 2 partners, and 4 health care professionals – are needed to participate in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Today, the researcher will ask you for a contact number and arrange a time to call you to ask if you would like to participate. If you choose not to participate you will not be contacted again. If you do wish to take part, you will be asked for a date when for the researcher can meet up with you. This could take place within you own home or in a private area in one of the hospital or University departments. You can withdraw from the study at any time and do not have to give a reason. Choosing not to take part, or choosing to withdraw from the study, will not affect the standard of care your partner receives in any way.

What will happen to me if I take part?

If you choose to take part you will be asked to take part in an informal interview. Your travel expenses will be reimbursed if you choose to have the interview away from your home. The interview will be conducted by the researcher you met with today, and will probably last for about 40 minutes. You will be asked about your experiences, how you think about the cancer, and whether you have a picture of it in your mind. You will be then be asked to describe and/or recreate any mental images you have using pens, pencils, or other materials – whichever method you found most helpful. If you do decide to recreate your images, the interviewer will ask you to describe what you are doing and what the images mean as you recreate them. If you agree the researcher will video you creating the images- your face will not be shown - and also tape-record what you say. However, these recordings will be treated confidentially and no-one other than the research team will know what you said or who you are. Any information which identifies you specifically will only be known to the research team. You are free to stop the interview at any time.

Audio recordings will be stored securely for up to three years and then destroyed. Video recordings will be stored indefinitely, but your face will not be recorded and these videos will also be stored in secured, locked drawers.

When writing up the results of this study, some direct quotes and some video images may be used, but these will always be anonymised – you will be given a false name and no identifiable information about you shall appear anywhere in the report.

The Tayside Research Ethics Committee have examined this project and approved it. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside.

How will the information I give be used?

The information you give us will help us to understand more about what head and neck cancer means to those who have it and their partners, and how people picture it. The results of this study will help us to understand how patients' partners' mental images of the illness can affect them, and perhaps suggest some ways we could help people to explore their beliefs about the illness through these images.

The information you give us will be collated with the interviews with other participants, to help us understand the different experiences of head and neck cancer. When the study is completed, the results of the study will be written up, presented to the funding body and the researcher's supervisors at the University of Dundee, and may be published in academic journals. If you would like, a copy of the results can be sent to you, and you can contact the researcher if you have any questions or wish to discuss your participation further.

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Who is funding this study?

The study is funded by the Chief Scientist Office. It is part of a PhD Studentship being undertaken by the researcher.

How can I get more information or contact you?

The researcher can be contacted by letter, telephone, or email.

Heidi Lang
Social Dimensions of Health Institute,
11 Airlie Place,
Dundee,
DD1 4HJ.

Telephone: 01382 386664
Email: hvlang@dundee.ac.uk

Thank you for taking the time to read this Information Sheet and considering taking part in this study.

Appendix 3: Pilot study HPs information sheet

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer Patients' Beliefs and Images: Pilot Study
PARTICIPANT INFORMATION SHEET – FOR HEALTH CARE PROFESSIONALS

You are being invited to take part in a research study. Before you decide whether or not you'd like to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. If there is anything which is unclear, or if you would like more information, please feel free to ask the researcher. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study involves talking to people who have been diagnosed with cancer of the head and neck, their partners, and relevant health care professionals, about different aspects of their experience of this illness. Some other studies involving patients with other illnesses have shown that the mental images that patients have of their illness can embody their beliefs and feelings about their illness. This study aims to look at the different ways that head and neck cancer patients may picture or imagine their cancer, from where these images originate and how they develop, the best ways of re-creating these images, and how mental images link to beliefs and feelings about the illness.

Why have I been invited to participate?

You have been invited to participate because you are a health care professional working with people with head and neck cancer, and we wish to learn about how you may use images and visual metaphors in your interactions with these patients. A total of approximately 12 people – 6 patients, 2 partners, and 4 health care professionals – are needed to participate in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Today, the researcher will ask you to consider participating and provide you with information about the study. You will be approached again at next week's clinic and asked whether or not you wish to take part. If you choose not to participate you will not be approached again. If you do wish to take part, you will be asked for a date and time when for the researcher can meet up with you for interview. The interview would take place within your work department. You can withdraw from the study at any time and do not have to give a reason.

What will happen to me if I take part?

If you choose to take part you will be asked to take part in an informal interview. Your travel expenses will be reimbursed if you choose to have the interview away from your home or work department. The interview will be conducted by the researcher you met with today, and will probably last for about 20 minutes. You will be asked about your use of visual metaphors and images during interactions with head and neck cancer patients. If you agree, the interview will be audio-recorded. However, these recordings will be treated confidentially and no-one other than the research team will know what you said or who you are. Any information which identifies you specifically will only be known to the research team. You will be free to stop the interview at any time.

Audio recordings will be stored securely for up to three years and then destroyed. When writing up the results of this study, some direct quotes may be used, but these will always be anonymised – you will be given a false name and no identifiable information about you shall appear anywhere in the report.

The Tayside Research Ethics Committee have examined this project and approved it. It is a requirement that your records in this research be made available for scrutiny by monitors from NHS Tayside.

How will the information I give be used?

The information you give us will help us to understand more about how health care professionals use images when talking to head and neck cancer patients. The results of this study will help us to understand how patients' mental images of their illness may be influenced by this.

The information you give us will be collated with the interviews with other participants, to help us understand the different experiences of head and neck cancer. When the study is

completed, the results of the study will be written up, presented to the funding body and the researcher's supervisors at the University of Dundee, and may be published in academic journals. If you would like, a copy of the results can be sent to you, and you will have the opportunity to discuss the study further with the researcher.

Who is funding this study?

The study is funded by the Chief Scientist Office. It is part of a PhD Studentship being undertaken by the researcher.

How can I get more information or contact you?

The researcher can be contacted by letter, telephone, or email.

Heidi Lang
Social Dimensions of Health Institute,
11 Airlie Place,
Dundee,
DD1 4HJ.

Telephone: 01382 386664
Email: hvlang@dundee.ac.uk

Thank you for taking the time to read this Information Sheet and considering taking part in this study.

Appendix 4: Main study patient information sheet

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer, Imagery, and Experiencing Treatment
PARTICIPANT INFORMATION SHEET

You are invited to take part in a research study that is being conducted in part fulfilment of a PhD award at the Universities of Dundee & St Andrews. Before you decide whether or not you'd like to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. If there is anything which is unclear, or if you would like more information, please feel free to ask the researcher. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study involves talking to people who have been diagnosed with cancer of the head and neck about their experience and understanding of their illness and treatment. We know that being diagnosed with cancer and going through treatment can be very demanding – both emotionally and physically. If we can learn and understand more about how cancer and treatment affects people we will be able to improve the support and care we provide. We know that patients' experiences of their illness and treatment are affected by their beliefs and understandings of cancer. We have already conducted a pilot study which showed that some patients with head and neck cancer have an image in their mind of what their cancer looks like and how it affects them. It seems that these mental images can be important in the ways people understand their illness and treatment.

This study aims to look at the different ways in which head and neck cancer patients understand and experience what is going on inside their bodies – both their cancer and the effects of the treatment. In the long term the findings of this study will enable us to identify how we might provide better support to patients and their families and improve people's experiences of head and neck cancer treatment.

Why have I been invited to participate?

You have been invited to participate because you have been diagnosed with a head and neck cancer and are undergoing a course of treatment, and we wish to learn about your experience of both the illness and treatment, and how you understand what is going on inside your body. A total of approximately 25 people are needed to participate in this study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. The nurse who gave you this Information Sheet will ask you if you'd be willing to speak to the researcher about the study when you next see or speak to her. If you do not wish to, you will not be approached again. If you would like to speak to the researcher about the study, the nurse will pass your contact details on to the researcher who will either telephone you or have a brief chat with you about the study when you next attend the hospital. After you've talked to the researcher, and if you wish to participate in the study, you will be asked for a date when for the researcher can meet up with you for the interview. This could take place within your own home or in a private area in one of the hospital or University departments. You can withdraw from the study <u>at any time</u> and do not have to give a reason. Choosing not to take part, or choosing to withdraw from the study, will not affect the standard of care you receive in any way.

What will happen to me if I take part?

If you choose to participate you will be asked to take part in two face to face interviews – the first within three weeks of beginning your treatment, and the second approximately one-two months after completing your treatment. Your travel expenses will be reimbursed if you choose to have the interviews away from your home. The interviews will be conducted by the researcher who you discussed the study with, and will probably last for between 45-60 minutes. You will be asked about your experiences and what you think might be going on inside your body. You will be then be asked to describe (and/or sketch if you would like to) any mental images you have of the cancer or the process of treatment. The interviews will be audio-recorded, but will be treated confidentially and no-one other than the research team will know what you said or who you are. Any information which identifies you specifically will only be known to the research team. You are free to stop the interviews at any time.

Audio-recordings will be stored securely until transcripts have been made and verified, and then the recordings will be destroyed. Transcripts of the interviews will be stored securely.

Any sketches you produce will be stored securely and retained indefinitely. They may be used in future publications or presentations, but will be anonymised and no-one will be able to identify you from the sketches. When writing up the results of this study, some direct quotes may be used, but these will always be anonymised – you will be given a false name and no identifiable information about you shall appear anywhere in the report.

Your medical notes may be consulted by the researcher in order to review demographic data and information about your illness and treatment, however the researcher holds an honorary contract with the NHS, which means she is bound by the same confidentiality agreement as other NHS staff (nurses, doctors etc). All information in your case notes will be kept confidential.

This study has been reviewed by a NHS Research Ethics Committee which has responsibility for scrutinising proposals for medical research on humans, in accordance with the requirements of the Clinical Trials Regulations. In this case, the reviewing Committee was the Fife & Forth Valley Research Ethics Committee who have raised no objections from the point of view of medical ethics.
It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from NHS Tayside.

How will the information I give be used?
The information you give us will help us to understand more about what head and neck cancer means to those who have it, how people understand their treatment, and how people picture it. The results of this study will help us to understand how patients' mental images of their illness and treatment can affect them, and how they can be helpful in understanding what is going on inside their bodies over the course of their treatment and beyond.

The information you give us will be collated with the interviews with other participants, to help us understand the different experiences of head and neck cancer/treatment. When the study is completed, the results of the study will be written up, presented to the funding body and the researcher's supervisors at the University of Dundee, and may be published in academic journals. If you would like, a copy of the results can be sent to you, and you can contact the researcher if you have any questions or wish to discuss your participation further.

Who is funding this study?

The study is funded by the Chief Scientist Office. It is part of a PhD Studentship being undertaken by the researcher.

How can I get more information or contact you?

The researcher can be contacted by letter, email, or telephone – there is an answering machine as the researcher is not always in the office, but will return any calls at the earliest opportunity.

Heidi Lang
Social Dimensions of Health Institute,
11 Airlie Place, Telephone: 01382 386664
Dundee, Email: hvlang@dundee.ac.uk
DD1 4HJ.

Alternatively, if you would prefer to talk to someone independent of the research project, you may contact Dr Gozde Ozakinci, a lecturer in Health Psychology at the University of St Andrews, who will be happy to discuss any questions or concerns you have about the study and/or participating in it.

Dr Gozde Ozakinci
Bute Medical School,
University of St Andrews,
St Andrews, Telephone: 01334 463521
Fife, Email: go10@st-andrews.ac.uk
KY16 9TS.

Thank you for taking the time to read this Information Sheet and considering taking part in this study.

Tayside Committee on Medical Research Ethics A

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	07/S1401/45	**Issue number:**	1	**Date of issue:**	29 May 2007
Chief Investigator:	Miss Heidi Lang				
Full title of study:	Illness Perceptions and Imagery: Exploring the Importance and Usefulness of Patients' Images of Cancer.				

This study was given a favourable ethical opinion by Tayside Committee on Medical Research Ethics A on 29 May 2007. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes* (1)
Miss Heidi Lang	CSO PHD Studentship	NHS Tayside	Tayside Committee on Medical Research Ethics A	14/05/2007	

Approved by the Chair on behalf of the REC:

..... (Signature of Chair/Co-ordinator)
(delete as applicable)

..... (Name)

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Fife and Forth Valley REC

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	08/S0501/5	**Issue number:**	0	**Date of issue:**	25 February 2008
Chief Investigator:	Ms Heidi Lang				
Full title of study:	Illness perceptions and imagery: Exploring the importance and usefulness of patients' images of cancer.				

This study was given a favourable ethical opinion by Fife and Forth Valley REC on 21 February 2008. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes* (1)
Miss Heidi Lang	CSO PHD Studentship	NHS Tayside	Tayside Committee on Medical Research Ethics A	25/02/2008	

Approved by the Chair on behalf of the REC:

..... (Signature of ~~Chair~~/Co-ordinator)
(delete as applicable)

FIONA BAIN ..... (Name)

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

POSITIVE ABOUT DISABLED PEOPLE

Appendix 6: Ethics approval letter for larger study

Appendix 7: Support services booklet – Pilot study

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer Patients' Beliefs and Images: Pilot Study

SUPPORT SERVICES INFORMATION FOR PARTICIPANTS

Thank you for participating in this study. Although we hope that your participation has not caused you any distress, we are aware that talking about cancer for research purposes can sometimes raise other questions and concerns.

If you would like to talk to someone about any of these issues, there are a number of organisations and support services that you can contact.

All services are free and confidential and are provided by professional and/or trained staff experienced in cancer care – except for 'Changing Faces' where the staff are experienced in issues relating to disfigurement.

Maggie's Dundee,
Ninewells Hospital,
Tom McDonald Avenue,
Dundee,
DD1 1ZVM

Maggie's Centres are for anybody who has, or who has had cancer. They are also for their families, their friends and their carers. Maggie's Dundee at Ninewells Hospital is open 5 days a week, from 9am - 5pm.

Maggie's Dundee helps people from across Dundee and Tayside learn how to manage the physical and emotional impact of living with cancer.

Maggie's Dundee offers a range of services aimed at helping people adjust to living with cancer. Its team of Cancer Support Specialists - including clinical or chartered counselling psychologists - facilitate group support, contribute to psycho-educational courses, and provide one-to-one support sessions.

Telephone: 01382 632 999 Email: dundee@maggiescentres.org
Fax: 01382 632998 Website: http://www.maggiescentres.org.uk

Tayside Cancer Support (T.C.S)
Room 12004
King's Cross Hospital
Dundee
DD3 8EA

Tayside Cancer Support (TCS) is a voluntary organisation which offers support, information and befriending for anyone affected by cancer - patients, relatives, friends and professionals. One-to-one support and open support meetings are free and confidential. One-to-one support is offered by the TCS Befriending Service. This support can be by telephone or face-to-face. Open support meetings are held on the second Monday of each month, at 7.15pm, in the Dundee Voluntary Association (DVA), 10 Constitution Road, Dundee. At these meetings people may give and receive support, reassurance and friendship, and listen to speakers on cancer-related and other topics.

Telephone: (01382) 596995 [24 hour voicemail] Email: support@tcs-dundee.org.uk
Fax: (01382) 425661 Website: www.tcs-dundee.org.uk/

Cancerbackup is a leading cancer information charity which provides practical advice and support for cancer patients, their families and carers. Their specialist cancer nurses can give you information about all types and aspects of cancer including: diagnosis, treatment, symptom control, clinical trials, support groups, where to get help and every other aspect of coping with cancer. They can also send you booklets written specifically for cancer patients, and a lot of information is available on their website. You can contact Cancerbackup's specialist cancer nurses by telephone, letter, or email. Phonelines are open Monday to Friday, 9am - 8pm.

Cancerbackup Scotland
Suite 2, 3rd Floor
Cranston House
Morrison Court
104/114 Argyle Street
Glasgow
G2 8BH

Freephone: 0808 800 1234
Telephone: 0141 223 7676
Fax: 0141 248 8422
Email: available on website
Website: http://www.cancerbackup.org/

WE ARE MACMILLAN. CANCER SUPPORT

The Macmillan CancerLine helps people living with cancer, and their family, friends and carers, find a way through the maze of cancer information and support in the UK.
It is open Monday to Friday 9am-10pm.
Specialist advisers can refer you to appropriate information and organisations, and listen to your particular issues with empathy and respect, and explain how Macmillan can help.
Calls are free and confidential. There is a translation service for people whose first language is not English and a textphone service for people who are deaf or hard of hearing.

Freephone: 0808 808 2020
Textphone: 0808 808 0121

Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

CancerHelp UK is one of Cancer Research UK's 5 main websites. CancerHelp UK provides information on a range of support services, and lists specific organisations that may be helpful to people with head and neck cancers and their relatives and friends.

CancerHelp UK
Cancer Information Department
Cancer Research UK
P.O. Box 123
Lincoln's Inn Fields
London
WC2A 3PX

Email: cancerhelpuk@cancer.org.uk
Website: http://www.cancerhelp.org.uk

Changing Faces is a national organisation which provides information, advice and counselling to people living with facial - and other – disfigurements, and their families. Services are free and confidential. Your GP or health/social care professional can contact Changing Faces on your behalf if you prefer. Changing Faces can also send you resources via post including booklets and videos on a number of topics related to disfigurement. A range of regional events and group workshops are also run throughout the year.

Changing Faces Scotland
PO Box 17326
Edinburgh
EH12 1BN

Phone: 0845 4500 275
Email: info@changingfaces.org.uk
Website: www.changingfaces.co.uk

Appendix 8: Support services booklet – Main Tayside

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer, Imagery, and Experiencing Treatment

SUPPORT SERVICES INFORMATION FOR PARTICIPANTS

Thank you for participating in this study. Although we hope that your participation has not caused you any distress, we are aware that talking about cancer for research purposes can sometimes raise other questions and concerns.

If you would like to talk to someone about any of these issues, there are a number of organisations and support services that you can contact.

All services are free and confidential and are provided by professional and/or trained staff experienced in cancer care – except for 'Changing Faces' where the staff are experienced in issues relating to disfigurement.

Maggie's Dundee,
Ninewells Hospital,
Tom McDonald Avenue,
Dundee,
DD1 1ZV

Maggie's Centres are for anybody who has, or who has had cancer. They are also for their families, their friends and their carers. Maggie's Dundee at Ninewells Hospital is open 5 days a week, from 9am - 5pm.

Maggie's Dundee helps people from across Dundee and Tayside learn how to manage the physical and emotional impact of living with cancer.

Maggie's Dundee offers a range of services aimed at helping people adjust to living with cancer. Its team of Cancer Support Specialists - including clinical or chartered counselling psychologists - facilitate group support, contribute to psycho-educational courses, and provide one-to-one support sessions.

Telephone: 01382 632 999 Email: dundee@maggiescentres.org
Fax: 01382 632998 Website: http://www.maggiescentres.org.uk

Tayside Cancer Support (T.C.S)
Room 12004
King's Cross Hospital
Dundee
DD3 8EA

Tayside Cancer Support (TCS) is a voluntary organisation which offers support, information and befriending for anyone affected by cancer - patients, relatives, friends and professionals. One-to-one support and open support meetings are free and confidential. One-to-one support is offered by the TCS Befriending Service. This support can be by telephone or face-to-face. Open support meetings are held on the second Monday of each month, at 7.15pm, in the Dundee Voluntary Association (DVA), 10 Constitution Road, Dundee. At these meetings people may give and receive support, reassurance and friendship, and listen to speakers on cancer-related and other topics.

Telephone: (01382) 596995 [24 hour voicemail] Email: support@tcs-dundee.org.uk
Fax: (01382) 425661 Website: www.tcs-dundee.org.uk/

Cancerbackup is a leading cancer information charity which provides practical advice and support for cancer patients, their families and carers. Their specialist cancer nurses can give you information about all types and aspects of cancer including: diagnosis, treatment, symptom control, clinical trials, support groups, where to get help and every other aspect of coping with cancer. They can also send you booklets written specifically for cancer patients, and a lot of information is available on their website. You can contact Cancerbackup's specialist cancer nurses by telephone, letter, or email. Phonelines are open Monday to Friday, 9am - 8pm.

Cancerbackup Scotland
Suite 2, 3rd Floor
Cranston House
Morrison Court
104/114 Argyle Street
Glasgow
G2 8BH

Freephone: 0808 800 1234
Telephone: 0141 223 7676
Fax: 0141 248 8422
Email: available on website
Website: http://www.cancerbackup.org/

WE ARE MACMILLAN. CANCER SUPPORT

The Macmillan CancerLine helps people living with cancer, and their family, friends and carers, find a way through the maze of cancer information and support in the UK.
It is open Monday to Friday 9am-10pm.
Specialist advisers can refer you to appropriate information and organisations, and listen to your particular issues with empathy and respect, and explain how Macmillan can help.
Calls are free and confidential. There is a translation service for people whose first language is not English and a textphone service for people who are deaf or hard of hearing.

Freephone: 0808 808 2020
Textphone: 0808 808 0121

Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

CancerHelp UK is one of Cancer Research UK's 5 main websites. CancerHelp UK provides information on a range of support services, and lists specific organisations that may be helpful to people with head and neck cancers and their relatives and friends.

CancerHelp UK
Cancer Information Department
Cancer Research UK
P.O. Box 123
Lincoln's Inn Fields
London
WC2A 3PX

Email: cancerhelpuk@cancer.org.uk
Website: http://www.cancerhelp.org.uk

Changing Faces is a national organisation which provides information, advice and counselling to people living with facial - and other – disfigurements, and their families. Services are free and confidential. Your GP or health/social care professional can contact Changing Faces on your behalf if you prefer. Changing Faces can also send you resources via post including booklets and videos on a number of topics related to disfigurement. A range of regional events and group workshops are also run throughout the year.

Changing Faces Scotland
PO Box 17326
Edinburgh
EH12 1BN

Phone: 0845 4500 275
Email: info@changingfaces.org.uk
Website: www.changingfaces.co.uk

Appendix 9 – Support services booklet – Main study Grampian

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Head & Neck Cancer, Imagery, and Experiencing Treatment

SUPPORT SERVICES INFORMATION FOR PARTICIPANTS

Thank you for participating in this study. Although we hope that your participation has not caused you any distress, we are aware that talking about cancer for research purposes can sometimes raise other questions and concerns.

If you would like to talk to someone about any of these issues, there are a number of organisations and support services that you can contact.

All services are free and confidential and are provided by professional and/or trained staff experienced in cancer care – except for 'Changing Faces' where the staff are experienced in issues relating to disfigurement.

CLAN House
Cancer Support Centre
Caroline Place
Aberdeen
AB25 2TH

Freephone: 0800 783 7922
Telephone: 01224 647000
Fax: 01224 640802
Email: enquiries@clanhouse.org
Website: http://www.clanhouse.org

Based at CLAN House, CLAN (Cancer Link Aberdeen & North) is an independent charity which provides services for people affected by any type of cancer and their carers, family members, and friends. Trained staff and volunteers can provide emotional support through face-to-face contact, or via telephone or email. The centre also offers advice and information about cancer, a range of relaxing complementary therapies, and runs various regular social activities.
CLAN House is open for you to drop-in: Mondays to Wednesdays 10am - 4pm, Thursdays 10am - 7pm, Fridays 10am - 4pm, and Saturdays 10am - 3pm

WE ARE MACMILLAN. CANCER SUPPORT

The Macmillan CancerLine helps people living with cancer, and their family, friends and carers, find a way through the maze of cancer information and support in the UK.
It is open Monday to Friday 9am-10pm.
Specialist advisers can refer you to appropriate information and organisations, and listen to your particular issues with empathy and respect, and explain how Macmillan can help.
Calls are free and confidential. There is a translation service for people whose first language is not English and a textphone service for people who are deaf or hard of hearing.

Freephone: 0808 808 2020
Textphone: 0808 808 0121

Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Cancerbackup is a leading cancer information charity which provides practical advice and support for cancer patients, their families and carers. Their specialist cancer nurses can give you information about all types and aspects of cancer including: diagnosis, treatment, symptom control, clinical trials, support groups, where to get help and every other aspect of coping with cancer. They can also send you booklets written specifically for cancer patients, and a lot of information is available on their website. You can contact Cancerbackup's specialist cancer nurses by telephone, letter, or email. Phonelines are open Monday to Friday, 9am - 8pm.

Cancerbackup Scotland
Suite 2, 3rd Floor
Cranston House
Morrison Court
104/114 Argyle Street
Glasgow
G2 8BH

Freephone: 0808 800 1234
Telephone: 0141 223 7676
Fax: 0141 248 8422
Email: available on website
Website: http://www.cancerbackup.org/

CancerHelp UK is one of Cancer Research UK’s 5 main websites. CancerHelp UK provides information on a range of support services, and lists specific organisations that may be helpful to people with head and neck cancers and their relatives and friends.

CancerHelp UK
Cancer Information Department
Cancer Research UK
P.O. Box 123
Lincoln's Inn Fields
London
WC2A 3PX

Email: cancerhelpuk@cancer.org.uk
Website: http://www.cancerhelp.org.uk

Changing Faces is a national organisation which provides information, advice and counselling to people living with facial - and other – disfigurements, and their families. Services are free and confidential. Your GP or health/social care professional can contact Changing Faces on your behalf if you prefer. Changing Faces can also send you resources via post including booklets and videos on a number of topics related to disfigurement. A range of regional events and group workshops are also run throughout the year.

Changing Faces Scotland
PO Box 17326
Edinburgh
EH12 1BN

Phone: 0845 4500 275
Email: info@changingfaces.org.uk
Website: www.changingfaces.co.uk

Appendix 10: Pilot study patient/partner consent form

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

CONSENT FORM – FOR PATIENTS AND PARTNERS

Title of Project: Head & Neck Cancer Patients' Beliefs and Images: Pilot Study

Name of Researcher: Heidi Lang

This form must be completed and signed by the research subject in the presence of someone with knowledge of the research designated by the Principal Investigator. This may be a doctor, nurse, clinical research assistant or other member of the research team who must countersign the form as witness to the subject's signature

Please tick (✓) appropriate box

1. Have you read and understood the Information Sheet (dated……, version……)? ……Yes ☐ No ☐
2. Have you been given an opportunity to ask questions and further discuss this study? ……Yes ☐ No ☐
3. Have you received satisfactory answers to all of your questions? ……Yes ☐ No ☐
4. Have you now received enough information about this study? ……Yes ☐ No ☐
5. Do you understand that your participation is entirely voluntary? ……Yes ☐ No ☐
6. Do you understand that you are free to withdraw from this study:
   - At any time? ……Yes ☐ No ☐
   - Without having to give a reason for withdrawing? ……Yes ☐ No ☐
   - Without this affecting your present or future medical care? ……Yes ☐ No ☐
7. Do you give permission for monitors from the following institutions to have access to your records in this research and supporting medical records where it is relevant to your participation in the study?
   - University of Dundee ……Yes ☐ No ☐
   - NHS Tayside ……Yes ☐ No ☐
   - Regulatory authorities ……Yes ☐ No ☐
8. Do you give permission for your interview to be audio-recorded? ……Yes ☐ No ☐
9. Do you give permission for any images you create to be video-recorded? ……Yes ☐ No ☐
10. Do you give permission for anonymised quotes and images to be used in written reports of this study? ……Yes ☐ No ☐
11. Do you agree to take part in this study? ……Yes ☐ No ☐

Name: …… Date: ……

Signature: ……

Telephone contact number: ……

Name of person taking consent: …… Date: ……

Signature: ……

Social Dimensions of Health Institute, Universities of Dundee and St Andrews,
11 Airlie Place, Dundee, DD1 4HJ.

Appendix 11: Pilot study Health Professionals consent form

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

CONSENT FORM – FOR HEALTH PROFESSIONALS

Title of Project: Head & Neck Cancer Patients' Beliefs and Images: Pilot Study

Name of Researcher: Heidi Lang

This form must be completed and signed by the research subject in the presence of someone with knowledge of the research designated by the Principal Investigator. This may be a doctor, nurse, clinical research assistant or other member of the research team who must countersign the form as witness to the subject's signature

Please tick (✓) appropriate box

1. Have you read and understood the Information Sheet (dated……,version……)? ……Yes ☐ No ☐
2. Have you been given an opportunity to ask questions and further discuss this study? ……Yes ☐ No ☐
3. Have you received satisfactory answers to all of your questions? ……Yes ☐ No ☐
4. Have you now received enough information about this study? ……Yes ☐ No ☐
5. Do you understand that your participation is entirely voluntary? ……Yes ☐ No ☐
6. Do you understand that you are free to withdraw from this study:
   - At any time ?……Yes ☐ No ☐
   - Without having to give a reason for withdrawing?…… ……Yes ☐ No ☐
7. Do you give permission for monitors from the following institutions to have access to your records in this research?
   - University of Dundee …… ……Yes ☐ No ☐
   - NHS Tayside …… Yes ☐ No ☐
   - Regulatory authorities …… ……Yes ☐ No ☐
8. Do you give permission for your interview to be audio-recorded? ……Yes ☐ No ☐
9. Do you give permission for anonymised quotes and images to be used in written reports of this study?…… Yes ☐ No ☐
10. Do you agree to take part in this study? ……Yes ☐ No ☐

Name: …… Date: ……

Signature: ……

Telephone contact number: ……

Name of person taking consent: …… Date: ……

Signature: ……

Social Dimensions of Health Institute, Universities of Dundee and St Andrews,
11 Airlie Place, Dundee, DD1 4HJ.

Appendix 12: Pilot study patient/partner topic guides

TOPIC GUIDE FOR INTERVIEWS WITH GROUP 1 – PATIENTS

1. Thank you for participating, settle in, and warm up conversation.
2. Go through consent form and information sheet and answer questions.
3. Tell me bit about your experience of cancer.
    - How it was discovered
    - Feelings at diagnosis
        i. How was the cancer described to you when you were diagnosed?
        ii. Use of any drawings, scans etc?
        iii. Were you shown any pictures throughout your treatment of the cancer or what the disease was doing to your body?
    - Treatment regimen
    - Support network
4. Summarise the impact being diagnosed with cancer has had on your life.
5. Tell me a bit about what cancer means to you.
    - Why do you feel you got it (as opposed to Mr Jones up the road)
    - What the word 'cancer' means to you (many people don't like using that word).
    - How your life has changed as a result of having cancer
    - How you feel about the future
        i. Cure or control, Timeline
6. Do you have, or have you ever had, a picture of cancer in your mind?
    - Could you describe this picture for me
    - What did this image mean to you
    - How did you feel when you pictured your cancer as you've described
    - Do you know why you picture it like you do
        i. Where this image might have come from
7. Could you recreate the image you've described?
        i. Not interested in your artistic skills
        ii. Use whichever materials you like
        iii. Video-recording
    - Describe what you're doing and why as you do it
8. Feelings about the re-creation
    - Accuracy
    - Happy with it

9. Now this picture you've created:
    - The only picture
        i. If not why chosen this one
    - The most prominent
    - Could you say at which times this image would occur to you
        i. When thinking of cancer, treatment, talking with friends, HPs, high level of worry
    - Has this picture changed at all during the course of your experience
10. What if I'd asked you to draw things in other ways
    - Your cancer
    - Cancer itself
    - How you see cancer in your mind
    - Your self
    - What cancer means to you
11. Other images
    - Describe these
    - Are they as prominent as the depicted one
    - What feelings do they evoke
    - Meaning
    - At which times do you think of them
    - Have they changed over time?
    - Willing to re-create these too
12. If you'd been asked to create your most prominent image of your cancer/cancer would you have picked different ones at different times?
    - Before diagnosis
    - Diagnosis
    - During or after treatment
13. Thinking back to what we discussed earlier, about the impact you feel cancer s had on your life, and what it means to you, can you see any ways in which the feelings you described there are illustrated in the images you created?
    - Sadness
    - Loss
    - Depression
    - Hope
    - Illness beliefs
14. Please complete this short questionnaire (Brief IPQ)

13. Thanks, questions, warm down conversation.

TOPIC GUIDE FOR INTERVIEWS WITH GROUP 1 – PARTNERS

1. Thank you for participating, settle in, and warm up conversation.
2. Go through consent form and information sheet and answer questions.
3. Tell me bit about your experience of your partner having cancer.
    - How it was discovered
    - Feelings at diagnosis
        i. How was the cancer described/explained to you when your partner was diagnosed?
        ii. Use of any drawings, scans etc?
        iii. Were you shown any pictures throughout your partner's treatment of the cancer or what the disease was doing to your partner's body?
    - Treatment regimen
    - Support network
4. Summarise the impact your partner having cancer has had on your life.
5. Tell me a bit about what cancer means to you.
    - Why do you feel your partner got it (as opposed to Mr Jones up the road)
    - What the word 'cancer' means to you (many people don't like using that word).
    - How your life has changed as a result of your partner's cancer
    - How you feel about the future (cure or control, timeline)
6. Do you have, or have you ever had, a picture of your partner's cancer in your mind?
    - Could you describe this picture for me
    - What did this image mean to you
    - How did you feel when you pictured your partner's cancer as you've described
    - Do you know why you picture it like you do (where this image might have come from)
7. Could you recreate the image you've described?
    - Not interested in your artistic skills
    - Use whichever materials you like
    - Video-recording
    - Describe what you're doing and why as you do it
8. Feelings about the re-creation
    - Accuracy
    - Happy with it
9. Now this picture you've created:
    - The only picture (If not why chosen this one)

- The most prominent
- Could you say at which times this image would occur to you (when thinking of cancer, treatment, talking with friends, HPs, high levels of worry)
- Has this picture changed at all during the course of your experience

10. What if I'd asked you to draw things in other ways
    - Your partner's cancer
    - Cancer itself
    - How you see cancer in your mind
    - Your partner
    - What cancer means to you
11. Other images
    - Describe these
    - Are they as prominent as the depicted one
    - What feelings do they evoke
    - Meaning
    - At which times do you think of them
    - Have they changed over time?
    - Willing to re-create these too
12. If you'd been asked to create your most prominent image of your partner's cancer/cancer would you have picked different ones at different times?
    - Before diagnosis
    - Diagnosis
    - During treatment
13. Thinking back to what we discussed earlier, about the impact you feel your partner's cancer has had on your life, and what it means to you, can you see any ways in which the feelings you described there are illustrated in the images you created?
    - Sadness
    - Loss
    - Depression
    - Hope
    - Illness beliefs
14. Please complete this short questionnaire (Brief IPQ)
15. Thanks, questions, warm down conversation.

Appendix 13: Pilot study HP topic guide

TOPIC GUIDE FOR INTERVIEWS WITH GROUP 2 –
HEALTH CARE PROFESSIONALS

1. Thank you for participating, settle in, and warm up conversation.
2. Go through consent form and information sheet and answer questions.
3. Tell me bit about your experience of working with head & neck cancer patients
    - How long
    - Why that patient group
    - Problems encountered
4. Are you aware that patients sometimes visualise their disease in their minds?
    - Experience of this
    - Anecdotes
5. What factors do you think may affect how patients visualise their illness?
6. Do you ever use visual language/metaphors when discussing head & neck cancer with patients (e.g. tumour like an orange)
    - How are these helpful
    - At which times have you used these (diagnosis, explaining treatments)
7. Do you ever sketch diagrams or pictures for patients
    - How are these useful
    - Content of these – willing to sketch an example
    - When produced
8. Do you consider your use of visual language and diagrams to be as extensive with head & neck cancer patients when compared to
    - Patients with other illnesses
    - Patients with other types of cancer
    - If it is used more, or less, with head and neck cancer patients – could you explain why this is
9. Thanks, questions, warm down conversation.

Strategy 1: Thesaurus Terms

No.	Medline	Embase	Cinahl	BNI	ASSIA	SSCI	PsycInfo
1	Qualitative Research/	qualitative stud$.mp.	Qualitative Studies/	qualitative stud$.mp.	(qualitative research	(qualitative research	(qualitative research
2	Nursing Methodology Research/	nursing methodology research.mp.	Research Nursing/	nursing methodology research.mp.	qualitative stud*	qualitative stud*	qualitative stud*
3	Questionnaires/	questionnaire/	Exp Questionnaires/	exp Research Methods/	nursing research methodology	nursing research methodology	nursing research methodology
4	exp Attitude/	attitude/	exp Attitude/	exp "patients attitudes and perceptions"/	Questionnaire	Questionnaire	Questionnaire
5	Focus Groups/	focus group$.mp.	Focus Groups/	focus group$.mp.	Attitude	Attitude	Attitude
6	Discourse analysis.mp.	discourse analysis.mp.	Discourse Analysis/	discourse analysis.mp.	focus group interviews	focus group interviews	focus group interviews
7	Content analysis.mp.	content analysis.mp.	Content Analysis/	content analysis.mp.	discourse analysis	discourse analysis	Discourse analysis
8	ethnographic research.mp.	ethnographic research.mp.	Ethnographic Research/	ethnographic research.mp.	content analysis	content analysis	content analysis
9	Ethnological research.mp.	ethnological research.mp.	Ethnological Research/	ethnological research.mp.	ethnographic research	ethnographic research	ethnographic research
10	ethnonursing research.mp.	ethnonursing research.mp.	Ethnonursing Research/	ethnonursing research.mp.	ethnological research	ethnological research	Ethnological research

11	Constant comparative method.mp.	constant comparative method.mp.	Constant Comparative Method/	constant comparative method.mp.	ethnonursing research	ethnonursing research	ethnonursing research
12	Qualitative validity.mp.	qualitative validity.mp.	exp Qualitative Validity/	qualitative validity.mp.	constant comparative method	constant comparative method	Constant comparative method
13	Purposive sample.mp.	purposive sample.mp.	Purposive Sample/	purposive sample.mp.	qualitative validity	qualitative validity	qualitative validity
14	observational method$.mp.	observational method$.mp.	exp Observational Methods/	observational method$.mp.	purposive sampl*	purposive sampl*	purposive sampl*
15	field stud$.mp.	field stud$.mp.	Field Studies/	field stud$.mp.	observational research	observational research	observational research
16	Theoretical sampl$.mp.	theoretical sampl$.mp.	Theoretical Sample/	theoretical sampl$.mp.	field stud*	field stud*	field stud*
17	phenomenology/	phenomenology/	Phenomenology/	phenomenology. mp.	theoretical sampl*	theoretical sampl*	theoretical sampl*
18	phenomenological research.mp.	Phenomenological research.mp.	Phenomenological Research/	phenomenological research.mp.	Phenomenology	Phenomenology	Phenomenology
19	Life experience$.mp.	life experience$.mp.	exp Life Experiences/	life experience$.mp.	phenomenological research	phenomenological research	phenomenological research
20	cluster	cluster	exp Cluster	cluster	life experiences	life experiences	life experiences

	sampl$.mp.	sampl$.mp.	Sample/	sampl$.mp.			
21	or/1-20[8]	or/1-20	or/1-20	or/1-20	cluster sample*)	cluster sample*)	cluster sample*)
22	exp Head and Neck Neoplasms/ or head and neck cancer.mp.	exp Head and Neck Tumors/ or exp Head and Neck Neoplasms/ or head and neck cancer.mp.	exp Head and Neck Tumors/ or exp Head and Neck Neoplasms/ or head and neck cancer.mp.	exp Head and Neck Cancer/	exp Head and Neck Cancer/	head and neck neoplasms.mp. or head and neck cancer.mp.	(head and neck cancer).mp.
23	21 and 22	21 and 22	21 and 22	21 and 22	#21 and #22	#21 and #22	#21 and #22

Strategy 2: Free-text Terms

No.	Medline	Embase	Cinahl	BNI	ASSIA	SSCI[9]	PsycInfo
1	ethnonursing.af.	ethnonursing.af.	ethnonursing.af.	ethnonursing.af.	(ethnonursing	(ethnonursing	ethnonursing.af.
2	ethnograph$.mp.	ethnograph$.mp.	ethnograph$.mp.	ethnograph$.mp.	ethnograph*	ethnograph*	ethnograph$.mp.
3	phenomenol$.af.	phenomenol$.af.	phenomenol$.af.	phenomenol$.af.	phenomenol*	phenomenol*	phenomenol$.af.
4	grounded theory.mp.	grounded theory.mp.	grounded theory.mp.	grounded theory.mp.	grounded theor*	grounded theor*	Grounded theory.mp.
5	(grounded adj (theor$ or study or studies or research or analys?s)).af.	(grounded adj (theor$ or study or studies or research or analys?s)).af.	(grounded adj (theor$ or study or studies or research or analys?s)).af.	(grounded adj (theor$ or study or studies or research or analys?s)).af.	grounded stud*	grounded stud*	(grounded adj (theor$ or study or studies or research or analys?s)).af.
6	((life stor$) or (women's stor$))	((life stor$) or (women's stor$))	((life stor$) or (women's stor$))	((life stor$) or (women's stor$))	grounded research	grounded research	((life stor$) or (women's stor$))
7	(emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or (participant observ$).tw.	(emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or (participant observ$).tw.	(emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or (participant observ$).tw.	(emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or (participant observ$).tw.	grounded analys?s	grounded analys?s	(emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or (participant observ$).tw.
8	((social construct$	((social construct$	((social construct$	((social construct$	life stor*	life stor*	((social construct$

	or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or (post modern$ or interpret$).mp.	or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or (post modern$ or interpret$).mp.	or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or (post modern$ or interpret$).mp.	or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or (post modern$ or interpret$).mp.			or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or (post modern$ or interpret$).mp.
9	(action research or cooperative inquir$ or (co operative inquir$) or (co-operative inquir$)).mp.	(action research or cooperative inquir$ or (co operative inquir$) or (co-operative inquir$)).mp.	(action research or cooperative inquir$ or (co operative inquir$) or (co-operative inquir$)).mp.	(action research or cooperative inquir$ or (co operative inquir$) or (co-operative inquir$)).mp.			(action research or cooperative inquir$ or (co operative inquir$) or (co-operative inquir$)).mp.
10	(humanistic or existential or experiential or paradigm$).mp.	(humanistic or existential or experiential or paradigm$).mp.	(humanistic or existential or experiential or paradigm$).mp.	(humanistic or existential or experiential or paradigm$).mp.	Emic	Emic	(humanistic or existential or experiential or paradigm$).mp.
11	(field adj (study or studies or research).tw.	(field adj (study or studies or research).tw.	(field adj (study or studies or research).tw.	(field adj (study or studies or research).tw.	Etic	Etic	(field adj (study or studies or research).tw.
12	(human science).tw.	(human science).tw.	(human science).tw.	(human science).tw.	hermeneutic*	hermeneutic*	(human science).tw.
13	(biographical method).tw.	(biographical method).tw.	(biographical method).tw.	(biographical method).tw.	Heuristic*	heuristic*	(biographical method).tw.
14	(qualitative	(qualitative	(qualitative	(qualitative	Semiotic*	semiotic*	(qualitative

	validity).af.	validity).af.	validity).af.	validity).af.			validity).af.
15	(purposive sampl$).af.	(purposive sampl$).af.	(purposive sampl$).af.	(purposive sampl$).af.	data saturat*	data saturat*	(purposive sampl$).af.
16	(theoretical sampl$).af.	(theoretical sampl$).af.	(theoretical sampl$).af.	(theoretical sampl$).af.	participant observ*	participant observ*	(theoretical sampl$).af.
17	((purpose$ adj4 sampl$) or (focus adj group$)).af.	((purpose$ adj4 sampl$) or (focus adj group$)).af.	((purpose$ adj4 sampl$) or (focus adj group$)).af.	((purpose$ adj4 sampl$) or (focus adj group$)).af.	Social construct*	social construct*	((purpose$ adj4 sampl$) or (focus adj group$)).af.
18	(account or accounts or unstructured or open-ended or (open ended) or text$ or narrative$.mp.	(account or accounts or unstructured or open-ended or (open ended) or text$ or narrative$.mp.	(account or accounts or unstructured or open-ended or (open ended) or text$ or narrative$.mp.	(account or accounts or unstructured or open-ended or (open ended) or text$ or narrative$.mp.	postmodern*	postmodern*	(account or accounts or unstructured or open-ended or (open ended) or text$ or narrative$.mp.
19	((life world) or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.	((life world) or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.	((life world) or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.	((life world) or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.	post structural*	post structural*	((life world) or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
20	(lived	(lived	(lived	(lived			(lived

	experience$).tw.	experience$).tw.	experience$).tw.	experience$).tw.			experience$).tw.
21	(life experience$.mp.	(life experience$.mp.	(life experience$.mp.	(life experience$.mp.	Interpret*	interpret*	(life experience$.mp.
22	(cluster sampl$).mp.	(cluster sampl$).mp.	(cluster sampl$).mp.	(cluster sampl$).mp.	action research	action research	(cluster sampl$).mp.
23	(theme$ or thematic).mp.	(theme$ or thematic).mp.	(theme$ or thematic).mp.	(theme$ or thematic).mp.	co-operative inquir*	co-operative inquir*	(theme$ or thematic).mp.
24	categor$.mp.	categor$.mp.	categor$.mp.	categor$.mp.	humanistic	humanistic	categor$.mp.
25	observational method$.af.	observational method$.af.	Observational method$.af.	observational method$.af.	existential	existential	observational method$.af.
26	Field stud$.mp.	Field stud$.mp.	Field stud$.mp.	Field stud$.mp.	experiential	experiential	Field stud$.mp.
27	focus group$.af.	focus group$.af.	focus group$.af.	focus group$.af.	Paradigm*	paradigm*	focus group$.af.
28	questionnaire$.mp.	questionnaire$.mp.	Questionnaire$.mp.	questionnaire$.mp.	field stud*	field stud*	questionnaire$.mp.
29	(content analysis).af.	(content analysis).af.	(content analysis).af.	(content analysis).af.	field research	field research	(content analysis).af.
30	(thematic analysis).af.	(thematic analysis).af.	(thematic analysis).af.	(thematic analysis).af.	human science	human science	(thematic analysis).af.
31	(constant comparative).af.	(constant comparative).af.	(constant comparative).af.	(constant comparative).af.	biographical method*	biographical method*	(constant comparative).af.
32	(discourse analys?s).af.	(discourse analys?s).af.	(discourse analys?s).af.	(discourse analys?s).af.	qualitative validity	qualitative validity	(discourse analys?s).af.
33	((discourse$ or discurs$) adj3 analys?s).tw.	((discourse$ or discurs$) adj3 analys?s).tw.	((discourse$ or discurs$) adj3 analys?s).tw.	((discourse$ or discurs$) adj3 analys?s).tw.	purposive sampl*	purposive sampl*	((discourse$ or discurs$) adj3 analys?s).tw.

34	(constant adj (comparative or comparison)).af.	(constant adj (comparative or comparison)).af.	(constant adj (comparative or comparison)).af.	(constant adj (comparative or comparison)).af.	theoretical sampl*	theoretical sampl*	(constant adj (comparative or comparison)).af.
35	(narrative analys?s).af.	(narrative analys?s).af.	(narrative analys?s).af.	(narrative analys?s).af.	open-ended account*	open-ended account*	(narrative analys?s).af.
36	heidegger$.tw.	heidegger$.tw.	heidegger$.tw.	heidegger$.tw.	unstructured account*	unstructured account*	heidegger$.tw.
37	colaizzi$.tw.	colaizzi$.tw.	colaizzi$.tw.	colaizzi$.tw.	Narrative*	narrative*	colaizzi$.tw.
38	speigelberg$.tw.	speigelberg$.tw.	speigelberg$.tw.	speigelberg$.tw.	life world	life world	speigelberg$.tw.
39	(van adj manen$).tw.	(van adj manen$).tw.	(van adj manen$).tw.	(van adj manen$).tw.	conversation analys?s	conversation analys?s	(van adj manen$).tw.
40	(van adj kaam$).tw.	(van adj kaam$).tw.	(van adj kaam$).tw.	(van adj kaam$).tw.	theoretical saturation	theoretical saturation	(van adj kaam$).tw.
41	(merleau adj ponty$).tw.	(merleau adj ponty$).tw.	(merleau adj ponty$).tw.	(merleau adj ponty$).tw.	Lived experience*	lived experience*	(merleau adj ponty$).tw.
42	husserl$.tw.	husserl$.tw.	husserl$.tw.	husserl$.tw.	life experience*	life experience*	husserl$.tw.
43	giorgi$.tw.	giorgi$.tw.	giorgi$.tw.	giorgi$.tw.	cluster sampl*	cluster sampl*	giorgi$.tw.
44	foucault$.tw.	foucault$.tw.	foucault$.tw.	foucault$.tw.	theme*	theme*	foucault$.tw.
45	(corbin$ adj2 strauss$).tw.	(corbin$ adj2 strauss$).tw.	(corbin$ adj2 strauss$).tw.	(corbin$ adj2 strauss$).tw.	Thematic analysis	thematic analysis	(corbin$ adj2 strauss$).tw.
46	(strauss$ adj2 corbin$).tw.	(strauss$ adj2 corbin$).tw.	(strauss$ adj2 corbin$).tw.	(strauss$ adj2 corbin$).tw.	Constant comparative	Constant comparative	(strauss$ adj2 corbin$).tw.
47	(glaser$ adj2 strauss$).tw.	(glaser$ adj2 strauss$).tw.	(glaser$ adj2 strauss$).tw.	(glaser$ adj2 strauss$).tw.	discourse analys?s	Discourse analys?s	(glaser$ adj2 strauss$).tw.

48	glaser$.tw.	glaser$.tw.	glaser$.tw.	glaser$.tw.	discurs*	discurs*	glaser$.tw.
49	or/1- 48	or/1- 48	or/1- 48	or/1- 48	Narrative analys?s)	Narrative analys?s)	or/1- 48
50	exp Head and Neck Cancer/ or exp Head and Neck Neoplasms/	exp Head and Neck Cancer/ or exp Head and Neck Neoplasms/ or exp Head and Neck Tumors/	exp Head and Neck Cancer/ or exp Head and Neck Neoplasms/ or exp Head and Neck Tumors/	exp Head and Neck Cancer/ or exp Head and Neck Neoplasms/ or exp Head and Neck Tumors/	(heidegger*	(heidegger*	(head and neck cancer).mp.
51	49 and 50	49 and 50	49 and 50	49 and 50	colaizzi*	colaizzi*	49 and 50
52					speigelberg*	speigelberg*	
53					van manen*	van manen*	
54					van kaam*	van kaam*	
55					merleau ponty*	merleau ponty*	
56					husserl*	husserl*	
57					giorgi*	giorgi*	
58					foucault*	foucault*	
59					corbin*	corbin*	
60					strauss *	strauss *	
61					glaser*)	glaser*)	
62					exp Head and Neck Cancer/	(head and neck cancer).mp. or (head and neck neoplasms).mp.	
63					#61 and #62	#61 and #62	

Strategy 3: Broad based Terms

No.	Medline	Embase	Cinahl	BNI	ASSIA	SSCI	PsycInfo
1	findings.af.	findings.af.	findings.af.	findings.af.	(findings	(findings	findings.mp.
2	Interview$.af. or Interviews/	Interview$.af. or Interviews/	interview$.af. or exp Interviews/	exp “interviews and interviewing”/	interview*	interview*	exp Interviews/ or interview$.mp.
3	qualitative.af.	qualitative.af.	qualitative.af.	qualitative.af.	qualitative)	Qualitative)	exp Qualitative Research/ or qualitative.mp.
4	or/1-3	or/1-3	or/1-3	or/1-3	exp Head and Neck Cancer/	(head and neck cancer).mp. or (head and neck neoplasms).mp.	Or/1-3
5	exp Head and Neck Neoplasms/ or head and neck cancer.mp.	exp Head and Neck Neoplasms/ or exp Head and Neck Tumor/ or head and neck cancer.mp.	exp Head and Neck Neoplasms/ or exp Head and Neck Tumor/ or head and neck cancer.mp.	exp Head and Neck Cancer/	#3 and #4	#3 and #4	(head and neck cancer).mp.
6	4 and 5	4 and 5	4 and 5	4 and 5			4 and 5

Appendix 15: CASP appraisal verdicts table

No	Paper	Consensus Verdict	Individual Verdicts		Apt Research Design		Sampling		Data Collection		Reflexivity		Ethical Issues		Data Analysis		Findings		Value of the Research	
			1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
1	Chou et al (2007) 1) BW and 2) GH	INCLUDE	Yes	Yes			Good	Good	Good		Poor		Poor	Poor	Good	Good	Good	Good	Good	
2	Gibson & McCombe (1999) 1) BW and 2) GH	EXCLUDE	No	No	Poor	Poor	Poor	Poor	Poor	Poor	Poor		Poor		FATAL	Poor			Poor	
3	Beck (2005) 1) BW and 2) HL	EXCLUDE	No	No	CASP tool inappropriate as not a research article - is a personal account. Reviewers used their individual judgement to recommend inclusion or exclusion															
4	Brouwer et al (1979) 1) MW and 2) HL	EXCLUDE	Uns-No	No	Poor	Poor	Poor	Poor	Poor	Good	Poor	Poor	FATAL	Poor		FATAL	Poor	Poor	Poor	Poor
5	Crossley (2003) 1) GH and 2) HL	INCLUDE	Yes	Yes	Good	Good	Poor	Good	Poor	Good	Poor	Good	Poor	N/A	Poor	Good	Poor	Good	Good	Good
6	Dobbins et al 2005 1) BW and 2) HL	Post-Discussion EXCLUDE	Uns	Uns	Good	Good	Poor	Poor	Poor	Good	Poor	Poor	Poor	Good	Poor	Unsure	Poor	Good	Poor	Good
7	Eardley, A. (1985) 1) GH and 2) HL	Post-Discussion EXCLUDE	No	Uns	Screen Q's	Good		Poor		Poor		Poor		Poor		Poor		Good		Poor
8	Eardley, A. (1986) 1) MW and 2) HL	Post-Discussion EXCLUDE	Uns	Uns	Poor	Good	Poor	Poor	Poor	Poor	Poor	Poor	Poor	Poor	FATAL	Poor	Poor	Good	Poor	Good
9	Edmonds & McGuire (2007) 1) BW and 2) HL	EXCLUDE	No	No	Not a research article - an article reviewing the literature. Therefore Exclude.															
10	Edwards, D. (1998) 1) GH and 2) HL	EXCLUDE – Focus is HNC Services	Yes	Uns	Good	Good	Good	Poor	Good	Good	Poor	Poor		Poor	Poor	Poor		Good	Good	Good
11	Feldman & Baker (1988) 1) GH and 2) HL	EXCLUDE	No	No	Screen Q's	Poor		Good		FATAL		Poor		Poor		FATAL		Poor		Poor

No	Paper	Consensus Verdict	Individual Verdicts		Apt Research Design		Sampling		Data Collection		Reflexivity		Ethical Issues		Data Analysis		Findings		Value of the Research	
			1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
12	Fritz, D.J. (2001) 1) GH and 2) HL	INCLUDE	Yes	Yes	Poor	Good	Poor	Poor	Good	Good	Poor	Good	Good	Good	Good	Good	Poor	Good	Good	Good
13	Furness, P.J. (2005) 1) MW and 2) HL	Post-Discussion EXCLUDE	Uns	Uns	Good	Good	Good	Poor	Good	Good	Poor	Poor	Good	Poor	Good	Unsure	Good	Good	Good	Good
14	Furness et al (2006) 1) BW and 2) HL	INCLUDE	Yes	Yes	Good	Good	Good	Good	Good	Good	Poor	Poor	Poor	Poor	Good	Good	Good	Good	Good	Good
15	Gamble, K. (1998) 1) GH and 2) HL	INCLUDE	Yes	Yes	Good	Good	Poor	Good	Good	Good	Good	Poor	Poor	Poor	Good	Good	Good	Good	Good	Good
16	Harris, R. (1995) 1) MW and 2) HL	Post-Discussion EXCLUDE	Yes	No	In-Btw.	Good	In-Btw.	Poor	Good	Good	Good	Good	Good	Good	Poor	FATAL	Poor	Good	Poor	Good
17	Hutton & Williams (2001) 1) GH and 2) HL	Post-Discussion EXCLUDE	No	Uns	Screen Q's	Good		Poor		Good		Poor		Poor		Poor		Good		Good
18	Jones, A. (2001) 1) BW and 2) HL	EXCLUDE	No	Uns-No		Good		Poor		Good		Good		Poor		Good		Good		Good
19	Jones, R.K. (2000) 1) GH and 2) HL	EXCLUDE	No	No	Screen Q's	Good		N/A		Poor		Poor		Poor		Good		Poor		Poor
20	Krouse, Krouse & Fabian (1989) 1) MW and 2) HL	EXCLUDE	No	No	Article is quantitative (and poor also). No qualitative data/analysis at all. Therefore Exclude.															
21	Krutchkoff & Eisenberg (1991) 1) GH and 2) HL	EXCLUDE	No	Uns.	CASP tool inappropriate as not a research article - is a personal account. Reviewers used their individual judgement to recommend inclusion or exclusion															
22	Laenger & Laenger (2004) 1) BW and 2) HL	EXCLUDE	No	Uns-No	CASP tool inappropriate as not a research article - is a personal account. Reviewers used their individual judgement to recommend inclusion or exclusion															
23	Larsson et al (2003) 1) BW and 2) HL	INCLUDE	Yes*	Yes	Good	Good	Poor	Good	Good	Good	Poor	Good	Good	Poor	Good	Good	Good	Good	Good	Good

No	Paper	Consensus Verdict	Individual Verdicts		Apt Research Design		Sampling		Data Collection		Reflexivity		Ethical Issues		Data Analysis		Findings		Value of the Research	
			1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
24	Larsson et al (2007) 'Needing a hand to hold…' 1) GH and 2) HL	INCLUDE	Yes	Yes	Good	Good	Good	Good	Good	Good	Good	Good	Good	Poor	Good	Good	Good	Good	Good	Good
25	Larsson et al (2007) 'A supportive nursing care…' 1) MW and 2) HL	EXCLUDE – Focus is HNC Services	Yes	Uns	Good	Good	Good	Good	Good	Good	Good	Good	Good	Poor	Good	Good	Good	Good	Good	Good
26	Llewellyn et al (2005) 1) MW and 2) HL	INCLUDE	Yes*	Yes	Poor	Good	Good	Poor	Good	Good	Poor	Poor	Good	Poor	Good	Good	Good	Good	Good	Good
27	Mah and Johnston (1993) 1) BW and 2) HL	Post-Discussion INCLUDE	Yes	No	Good	Good	Poor	Poor	Good	Poor	Poor	Poor	Poor	Poor	Poor	Good	Good	Good	Good	Good
28	McLane et al (2003) 1) BW and 2) HL	EXCLUDE – Focus is HNC Services	Yes	Uns	Good	Good	Poor	Good	Good	Good	Poor	Poor	Good	Poor		Good	Good	Good	Good	Good
29	Minear & Lucente (1979) 1) GH and 2) HL	EXCLUDE	No	No	Screen Q's	Good		Poor		Poor		Poor		Poor		FATAL		Poor		Poor
30	Moore et al (2004) 'A qualitative study…' 1) BW and 2) HL	EXCLUDE as duplicate	Yes	No	Good	Good	Good	Good	Good	Good	Poor	Poor	Good	Good	Poor	FATAL	Poor	Good	Good	Good
31	Moore et al (2004) 'Communicating suffering…' 1) MW and 2) HL	Post-Discussion INCLUDE	Yes	No	This article is a virtual carbon-copy of the above. Reporting on the same study, in the same way (word for word in many areas), same findings and same flaws – refer to Moore (2004) 'A qualitative study…' CASP for details.															
					Good		Good		Good		Poor		Poor		Poor		Poor		Good	
32	Newell et al (2004) 1) MW and 2) HL	Post-Discussion EXCLUDE	Uns	No	Good	Good	Good	Good	Good	Good	Poor	Poor	Poor	Poor	In-Btw.	FATAL	Poor	Good	Good	Good

No	Paper	Consensus Verdict	Individual Verdicts		Apt Research Design		Sampling		Data Collection		Reflexivity		Ethical Issues		Data Analysis		Findings		Value of the Research	
			1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
33	Oakley (1979) 1) BW and 2) HL	EXCLUDE	No	Uns	CASP tool inappropriate as not a research article - is a personal account. Reviewers used their individual judgement to recommend inclusion or exclusion															
34	Piff, C. (2000) 1) MW and 2) HL	EXCLUDE	No	Uns	CASP tool inappropriate as not a research article - is a personal account. Reviewers used their individual judgement to recommend inclusion or exclusion															
35	Richardson, Lee, & Birchall (2002) 1) GH and 2) HL	EXCLUDE – Focus is HNC Services	Yes	No	Good	Good	Good	Good	Good	Good	Poor	Poor	Good	Poor	Poor	FATAL	Good	Good	Good	Good
36	Rodriguez & VanCott (2005) 1) BW and 2) HL	Post-Discussion INCLUDE	Yes	Uns	Good	Good	Poor	Good	Good	Good	Poor	Poor	Good	Good	Good	Poor	Good	Good	Good	Good
37	Roing et al (2007) 1) MW and 2) HL	INCLUDE	Yes	Yes	Good	Good	Good	Good	Good	Good	Good	Poor	Good	Good	Good	Good	Good	Good	Good	Good
38	Rose-Ped et al (2002) 1) BW and 2) HL	EXCLUDE	No	No	Good	Good	Good	Poor	Good	Poor	Poor	Poor	Poor	Poor	FATAL	FATAL	Poor	Poor	Poor	Poor
39	Sahachowdhury, S. (2000) 1) MW and 2) HL	EXCLUDE	No	No	Screen Q's	Poor		Poor		Poor		Poor		Poor		Poor		Poor		Poor
40	Scott et al (2006) 1) GH and 2) HL	Post-Discussion INCLUDE	Yes	Uns	Good	Good	Good	Good		Good	Poor	Poor	Good	Poor	Good	Good	Good	Good	Good	Good
41	Scott et al (2007) 1) BW and 2) HL	Post-Discussion INCLUDE	Yes	Uns	Good	Good	Good	Good	Good	Good	Poor	Poor	Good	Poor	Good	Good	Good	Good	Good	Good
42	Sharp & Tishelman (2005) 1) MW and 2) HL	EXCLUDE – Focus is HNC Services	Yes	Uns	Poor	Good	Good	Good	Good	Good	Good	Poor	Good	Poor	Good	Good	Good	Good	Good	Good
43	Strauss, R.P. (1989) 1) MW and 2) HL	Post-Discussion EXCLUDE	Uns	No	Good	Good	Poor	Poor	Poor	Poor	Poor	Poor	FATAL	Poor	Poor	FATAL	Poor	Poor	Poor	Poor

No	Paper	Consensus Verdict	Individual Verdicts		Apt Research Design		Sampling		Data Collection		Reflexivity		Ethical Issues		Data Analysis		Findings		Value of the Research	
			1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2	1	2
44	WattWatson & Graydon (1995) 1) GH and 2) HL	EXCLUDE	No	No	Screen Q's	Good		Poor		Poor		Poor		Poor		FATAL		Poor		Good
45	Wells (1998) 1) GH and 2) HL	INCLUDE	Yes	Yes	Good	Good	Poor	Poor	Good	Good	Good	Poor	Good	Good	Good	Good	Good	Good	Good	Good
46	Whittington, E. (2005) 1) MW and 2) HL	EXCLUDE	No	No	CASP tool inappropriate as not a research article - is a personal account. Reviewers used their individual judgement to recommend inclusion or exclusion															
47	Wilson, Herman, & Chubon (1991) 1) BW and 2) HL	EXCLUDE	No*	No	Good	Good	Good	Good	Good	Good	Poor	Poor	Poor	Poor	FATAL	Poor	Good	Good	Poor	Good

Appendix 16: Main study introductory letter - Tayside

******* ******

Oncology & Radiotherapy Support Team

Cancer Network Office

Ward 32

Ninewells Hospital

DD1 9SY

Dear

The patient information sheet which accompanies this letter provides details of a research study which is currently being undertaken in the Radiotherapy & Oncology Department. The consultants and I have given our full support to this study, and invite you to read the patient information sheet attached. Thank you very much.

Yours sincerely,

Appendix 17: Main study introductory letter - Grampian

Oncology - Clinic D
Aberdeen Royal Infirmary
Foresterhill
Aberdeen
AB25 2ZN

Dear

The patient information sheet which accompanies this letter provides details of a research study which is currently being undertaken within our department. We have given our full support to this study and invite you to read the patient information sheet attached.
Thank you very much.

Yours sincerely,

Appendix 18 – Main study T1 topic guide

TOPIC GUIDE FOR INTERVIEW 1

- Thank you for participating
- Any questions? – Confidentiality, refuse to answer
- Consent form
- GP letter – take address
- Demographics details
- Disease details

……

- Your experience of cancer so far.
  - Prior experience – own or familial
  - Current cancer – symptoms, diagnosis, cause
- What does cancer mean to you
  - What is it – Could you describe cancer to me as you understand it (identity)
  - What does it do – its physical action, the consequences
  - What are its characteristics – what is it made of, how does it originate
  - How do you feel about it
  - Where does this understanding come from – previous knowledge, HPs
- What do you think is going on inside your body right now?
  - Are the disease effects local or far-reaching
  - Location
  - Behaviour
  - If untreated?
- Mental Image
  - Ever thought about what it looks like?
  - Do you have a picture of it in your mind's eye?
- Tell me a bit about the treatment you're going to be having
  - Understanding - Could you describe this treatment to me as you understand it
  - Fears/expectations
  - What will it do – its action on the cancer
  - What happens to the cancer?
- Exposure to imagery
  - Visual language
  - Scans, nasoendoscope, HP language

…..

- Impact of cancer on your life
    - Emotionally – Work – Relationships – Leisure

……

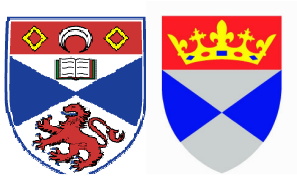
- Anything you would like to add?
- Support Services Booklet
- Arranging 2nd interview
- Any questions?
- Thanks

Appendix 19: Main study T2 topic guide

TOPIC GUIDE FOR INTERVIEW 2

- Thank you for participating, settle in, and warm up conversation.
- Recap last interview and answer questions.
- Tell me a bit about how things have been going (the experience)
- And how did your treatment go
    - Visual language
    - Practical experience
    - Its action/aim
    - Side effects – expected and actual
- What do you think is going on inside your body now?
    - With the cancer
    - After the treatment – i.e. in terms of affected tissues etc
- Mental image of the cancer
    - This is the drawing you produced last time – is it still relevant
    - Any changes in the way you visualise it
    - Any other images
    - What kind of feelings did/does this image bring up
    - How do you now envision the site where the cancer has been
- Tell me about how your beliefs/understanding/expectations have changed over time
    - What cancer means
    - What the treatment is like
- Thoughts about the future
    - How will your body be – i.e. as before, forever changed etc
    - What does recovery mean
    - Fears/expectations
- Thanks, questions, warm down conversation.

Appendix 20: Main study consent form



Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: 'Head & Neck Cancer, Imagery, and Experiencing Treatment'
Name of Researcher: Heidi Lang

Please Initial Box

1. I confirm that I have read and understand the information sheet dated ..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Dundee, from regulatory authorities or from the NHS Tayside, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree that the researcher may obtain information from my case notes in order to obtain some basic details about me, my illness and its treatment. ☐

5. I agree that any sketches of my tumour I produce in this study may be kept indefinitely and used in future publications or presentations. ☐

6. I agree to my GP being informed of my participation in the study ☐

7. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
Name of Person Taking Consent	Date	Signature

Appendix 21: Application to REC for inclusion of 2nd site

Social Dimensions of Health Institute (SDHI)

Universities of Dundee & St Andrews

3rd July 2008

REC reference: 08/S0501/5
Short title of study: Head & Neck Cancer, Imagery, and Experiencing Treatment
Full title of study: Illness perceptions and imagery: Exploring the importance and usefulness of patients' images of cancer

Dear Sir/Madam,

I write to inform the committee of a minor amendment to the above ongoing study. We would like to add a second site for recruitment purposes, this being NHS Grampian. This is due to an unprecedented lull in the number of new patients coming through our first site. I understand this is an SSA-exempt study, and that therefore this is not a substantial amendment.

We have approached the Oncology Department of Aberdeen Royal Infirmary (ARI), and sought the consent of the appropriate persons to recruit from there. *******, who is the Neurology/Head and Neck Nurse at ARI, has agreed to identify eligible patients at this site, distribute the patient information sheets to them, and seek provisional agreement for the researcher (myself) to contact them, whereby I will seek their consent to participate in the study. This is the same recruitment procedure which has been employed at our first site (NHS Tayside, Ninewells Hospital Oncology Dept).

******* can be contacted via telephone, email, or letter as indicated below
Telephone: ARI switchboard 0845 456 6000 ext. *****
Email: *******@arh.grampian.scot.nhs.uk
Address: c/o Clinic D, Aberdeen Royal Infirmary, Foresterhill, Aberdeen, AB25 2ZN.

Please advise of any further steps to be taken by ourselves in order to secure approval for incorporating this second site into our study. I look forward to hearing from you.

With best wishes,

Heidi Lang

Appendix 21: REC approval letter for inclusion of 2nd site

NHS Fife NHS Forth Valley NHS Tayside

Fife, Forth Valley & Tayside Research Ethics Service

Fife & Forth Valley Research Ethics Committee
Research Ethics Office
Level 9
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Ms Heidi Lang
CSO PhD Studentship
Social Dimensions of Health Institute
Universities of Dundee & St Andrews,
11 Airlie Place
DUNDEE
DD1 4HJ

Date: 17 July 2008
Your Ref:
Our Ref: FB/LR/**08/S0501/5**
Enquiries to: Miss Fiona Bain
Extension: Ninewells extension 32701
Direct Line: 01382 632701
Email: fionabain@nhs.net

Dear

Study title:	**Illness perceptions and imagery: Exploring the importance and usefulness of patients' images of cancer.**
REC reference:	**08/S0501/5**
Amendment number:	**1**
Amendment date:	**03 July 2008**

Thank you for your letter of 08 July 2008, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment		03 July 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/S0501/5	**Please quote this number on all correspondence**

Yours sincerely

L. Reilly

Mrs Lorraine Reilly
Assistant Administration Manager for
Fife, Forth Valley & Tayside Research Ethics Service

Copy to: Mr Andrew Spencer, R&I, University of Dundee
NHS Tayside R&D Office

49th All Nodes Inventory

.....

FREE NODES

A ----------

- A Bizarre Side Effect of Chemo – Renewal of Hair Growth
- A Changed Body Post-Surgery
- A New Normality
- Absence of symptoms means reliant on HPs to spot recurrence
- Acceptance of HPs' Info-Giving Choices
- Accessing Support Services
- Affects Partners-Family Also
- After-Care is Fragmented
- After Treatment – Lack of Support
- After Treats the C is Just Gone – Never Thought About How
- An Experience of Shit Care
- An Unexpected Turn for the Worse
- Anger About the Cancer is Repressed
- Annoyance that Cancer Services must be Provided by Charities (not gov't)
- Anxiety re When the Cancer Will Return
- Appearance Changes Don't Bother Me
- Appearance Changes = Loss of Confidence
- As Own C Curable Feel Any Recurrence Would Be Too
- Attitude to medicine
- Attitude to Smoking-Alcohol
- Avoiding Imagery due to Fear

B ----------

- Believe C Recurr Actually as Never Gone the 1st Time
- Believe Cancer Imagery Depends on Brain's Visual or Written Preference
- Believe Reason Told to Drink Lots Through Chemo as Can't Eat
- Believe Recurrence Would Present (Symptoms) As Per Initial Cancer
- Believed C Would be Painful But It Wasn't
- Beyond HNC – Changed Outlook – Realise Value of Life
- Beyond HNC – Discovery of An Aneurysm
- Beyond HNC – Don't Think the Future is Changed or That will Worry Much re Recurrence
- Beyond HNC – Appreciate the Little Things in Life More (which took for granted)
- Beyond HNC – Have Become More Emotional
- Beyond HNC – My Outlook Hasn't Changed
- Beyond HNC – Realise Am Stronger Than I Thought
- 'Bland is Grand' – Imposed Dietary Changes (treats impact)
- Bonding with Fellow Patients
- Bored, Lonely and Isolated but Can't Motivate Self to 'Do Something' (Depressed)
- Burning of the Skin (treat
- impact) *[Changed from 'Reddening']*

C ----------

- C Affects People Differently
- C Brought Us Closer Together
- C Cells Spread By Multiplying and 'Taking Over' Good Cells
- C Cells Do Not Die Off As Per Normal Cells
- C Does – Starts as Couple Cells then Travels, Latches On Somewhere, and Forms Tumour
- C Doesn't Cause Pain
- C is 'A Beast' (Powerful, Indiscriminate)
- C is 'Sneaky and Brilliant' (character)
- C Secondaries are Incurable (severity)
- CT Scan Contrasting Agent was a Horrible Experience
- Cancer is a 'Natural' Disease ('part of the natural cycle')
- Cancer is Indiscriminate
- C Dominates the Mind
- C Family Response
- C Fear of Spread
- C First Symptoms (Timeline-Identity)
- *C Identity – Not a Spread from Own Concurrent Cancer*
- *C Must Spread as it Grows and 'Runs out of Room'*
- C Image – Can Picture It As Know Where It Is
- C Initial Reaction Shock-Crying then
- C is a Private Matter – 'Dealt With It In-House'
- C is A Problem To Be Dealt With
- C is Often in the News
- C is Surreal When Feel Well *[Not new node but moved from +C Reaction - +To Diagnosis]*
- C Previous Experience
- *C Seeks Out Weaknesses in Own Body*
- *C Spread – Some bits will, perhaps other bits won't*
- C Static – Never thought about what it was doing-Behaviour
- C Survival Rates Improved Now
- C Timeline

Appendix22 – Example master list of themes showing how the process of coding was documented and illustrating the broad scope of the study data

Those highlighted yellow are yet to be restructured. New Nodes at Steve 2, Andrew 2, Nell 2, Alasdair 2, Jill 2, Lewis 2, Albert 2, Olive 2, Eric 2, Katrina 2, Jean-Claude 2, Christopher 2, restructuring part 7, Brian 2, Ashley 2, Lesley 2, Cathy 2, Barry 2, Scott 2, and Alan 2. New nodes created and nodes modified during *Restructuring Part 8.*

- C Will Always Be at the Back of My Mind
- Can Be Incurable Despite HPs' Best Efforts
- Cancer 'Hijacks' Your Body's Resources
- Cancer Affects 'Every Aspect of My Life'
- Cancer Becomes the 'Backdrop to Your Life'
- Cancer 'Creeps Up On You'
- Cancer Dominates Your Life During Treatment (and your family's)
- Conflict with Partner Born out of Strain-Her Fears
- Cancer is Caused by a Complex Combination of Factors
- Cancer Cells Attack a 'Weak Point' in Your Body
- 'Cancer' Doesn't Conjure an Image But 'Tumour' Does
- Cancer-Physical Changes Did Not Inhibit Intimacy with Partner
- Cancer is Not Mechanical (i.e. Surgically Curable)
- Cancer Wrecked My Happiness
- Ch Does – Kills Off Cancer Cells
- Ch Nature – Continues Working for Some Time After Sessions
- Coping with Life Stuck in Hosp – Keeping Busy
- Care in Hospital Positive
- Ch Nature – Body Can Only Endure So Much at One Time
- Chemo May Cause Long-Term Problems re Dentistry
- Chemo SE Far Less Difficult Than Ra SE
- Chemo – Unsure if it Affects the Rest of Your Body
- Cheated of Future
- Character of Cancer – 'Dirty'
- Chemo Had No Preconceptions
- Ch – Previously Thought it was 'Getting Zapped with Radiation'
- Chemo Pump is Disruptive-Awkward
- Chemo Pump Inefficient (Malfunctioned)
- Chemo Pump Nature – Administers Drugs in 24-Hour Cycles
- Chemo Took Longer than Expected to Have Desired Effect
- C is a Whole New Experience
- Children Responded with More Concern
- Cleanliness Level in Hospital Poor
- Combined Impact (SE) of Ra and Ch
- Concealing Neg Emotions
- Conceding the Need for the PEG Feed
- Confusion at Diag over Terminology
- Commentary while Drawing
- *Concurrent Kidney Cancer has Spread to Lungs*
- Contact with HPs Valuable when Socially Isolated

D ----------

- Declining to Draw an Image
- Deciding Against Aggressive Treat – Slim Cure Chance – 'Don't Care Enough'
- Delayed Help-Seeking
- Delayed Treatments (HPs-Services Negative)
- Dislike the word 'Remission' as Implies Recurrence is Inevitable
- During Treat – A New Normality
- Depression – Massive Lack of Motivation
- Depression Post-Treat Makes it Hard to Put Weight Back On
- Developing a Bond with other C Patients
- During It Busy Trying to Protect Family – After Emotional Enormity Hits
- Desire to Help Others
- Desire for Independence-Normalcy Conflicts with Need for Help
- Desire to get off Morphine Leads to Agonising Withdrawal Attempt
- Desire to Give Something Back to the HPs who Cared for Me So Well
- Desire to 'Move On' Post-Treat and No Longer Have Cancer Dominate my Life
- Despite Massive Weight Loss Unaware of-Not Offered PEG Feed
- Despite SE Never Any Question of Not Carrying On
- Didn't Realise How Major Operation Was Until After
- Disappointed HPs Unwilling to Operate (Risk to Life)
- Disliking the Word Cancer
- Do Not Visualise Treatments Action on the Cancer
- Don't Have Any Worries re Site Post-Treatment (i.e. Damage)
- During Treatment – Is It Worth It

E ----------

- Easy Acceptance of Limitations Imposed by SE
- Eating Ability Back to Normal Post-Treat
- Elation at Treatment End Curbed by Lingering Impairments
- Enjoying Life
- Embracing Self-Care with Partner's Support
- Excess Saliva Production (Treats Impact)
- Expectations (general)
- *Expect No Lasting Damage to Voice from Surgery*
- Expect Ra SE to be Worst at End of Treatment
- Expect Ra SE to Disappear Soon Post-Treatment
- Expect Ra SE to Improve 'Once Get Used to It'
- Experience of C is Just Another Part of My Life

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- Experience was Surreal (Traumatic)

F ----------

- Facing up to Reality
- Family Try to be Supportive
- Feel a Bit Like HPs are 'Not Bothered' About You Post-Treat
- Fear It May Kill Me
- Fear of How Sick I Might Become
- Fear of How the Cancer Might Affect Me
- Fear of Recurrence Beyond HNC
- Fear of Recurrence Heightened by HPs' Delay in Diagnosis
- Fear of Recurrence is More Fear of Having to go Through the Treatments Again
- Fear of the Potential Severity (i.e. Length) of Treatments
- Fear Spread to Brain Will Impair Ability to Control Life
- Fed Up Having to Talk About It
- Feel Able to Access Support Post-Treatment
- Feel My Cancer is a 'Punishment' (Guilt Over Partner's Death)
- Feel a bit Mistrustful of Good News at Follow-Up Appts (unsure whether HPs wrong in saying was 'clear' previously)
- Friends Responded Helpfully-Positively
- Feel Angry in Retrospect about what Cancer 'Has Cost Me'
- Feel Have 'Lost Myself' as Crippled by Lack of Confidence Post-Treat
- Feel Loss of Partner due to Cancer-Induced Changes in Me (Physical and Personality)
- Feel Partner was Embarrassed to be Seen with Me Looking Ill
- Feel Self-Conscious Eating in Public
- Finishing Treats-Getting Home – 'Euphoric'
- Feelings About Dying
- Financial Worries
- Family Responded Well – Felt Had a Duty to Tell Them
- Finding-Focussing on the Positives (coping)
- Follow-Up Appts are a Necessary Evil
- Follow-Up Appts are Anxiety-Provoking (Fear Recurrence)
- Follow-up Appts are Reassuring
- Friend's Obsessive Questioning of me re the Cancer is Unhelpful-Distressing

G ----------

- Gaps in Knowledge
- General Treatment Imagery
- 'Glad' I Got Cancer Rather Than My Family
- Got Used to the Claustrophobia of Ra – 'A Bit Scary'
- Gradual Improvement in SE Post-Treatment
- Grateful for-Respectful of HPs' Efforts

H ----------

- Hard to Trust a Changed Prognosis (Terminal to Cancer-Free)
- Has Never Seen Any Pictures of Cancer
- Have had Days of Utter Despair despite Striving to Stay Positive
- Have Not Thought Too Much About the Ra in Advance
- Have Visual Conception of the C Despite Uncertainty re It
- Have Had Only the 'Odd Down Day' During the Experience
- Have Learnt a Lot about Cancer Since being Diagnosed
- HNC is Neglected Publicity- and NHS Priority-Wise
- HPs are Insensitive to the Fact You are a Person with a Life Outside Treatments
- Having Cancer – 'A Year Out' from Normal Life
- Having Cancer Creates New Worry re Partner's Life
- Having the Voice-Box Removed Would be the 'Worst Thing'
- HNCs Are Rarer Than Other Cancers
- HNC is...
- HNC 'Particularly Vile' Due to High Risk of Spread
- How Does Chemo Identify Which Are Cancer Cells
- Have 'Good and Bad Days' with Symptoms
- HPs Understand Difficulties and Try to Help
- HPs are Approachable with Q's
- HPs Explanation of Specific Problem and Their Plan to Fix It is Reassuring
- HPs Dismissive of the Difficulties of Treatments
- HPs Responded Well to Difficulties
- Hope-Desire for Return to Normality Post-Treatment
- Hope Lingering SE Will Clear
- How Does Cancer Kill You?

I ----------

- 'If I Can't Get Better Nobody Will' – Well-Placed to Survive
- Image of the Cancer – Did Not Dwell On This
- Image of the Site Post-Treatment – Shown Scan
- Image of the Cancer has Low Emotional Impact or Prominence in Mind
- Image Salience

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- Image Stability – 'That's How I See It'
- Impact of Treatments (SE)Worse Than Anticipated
- Impact on Relationship - Brought Us Closer Together
- Impatient for Normality
- Impatient for treatment
- Imagery = Better Understanding = Better Compliance
- Imagery as Helpful as Increases Understanding
- Imagery Speculative - About What I Didn't Imagine
- Imagery – C Cells are Similar to Normal but Densely Packed and 'Squashed Together'
- Imagery – Cancer Cells Contaminate Surrounding Tissues
- Imagery – Since T1 Researched what C Cells Look Like
- Imagery of the Cancer-Site Based on How Treatments Affect It
- Imagery of Cancer-Site Based on Symptoms
- Imagery of the Post-Treat Site
- Imagery (metaphorical) of Treatment SE
- Imagery re Nature of Treatments – 'Carpet Bombing'
- Imagery re Nature of Treatments – Ch 'beats you up'
- Imagery Related to Treatment Side Effects
- Imagery – Metaphorical of Treatments
- Imagery not Spontaneous but Represents Feelings About the Cancer
- *Imagery (Various) 'Filling in the Gaps'*
- Incurable – Treatments to Improve QoL
- Initially Confused and Believed was Having Chemo (Not Ra)
- Interpreting Bodily Changes and Side Effects
- *Interpreting Diagnosis (Own Cancer)*
- Interpreting HPs Behaviour (see Kirk re scan + others – v important)
- *Interpreting Impact of Treatments on the Cancer (Evolution of Perception of Site-Image)*

J ----------

- Joy at Finishing Treatment

K ----------

- Knowing Ra was the Final Treat Hurdle (only precautionary) Made it Easier to Bear

L ----------

- Lack of Control over Treatments
- Lack of Normality and the C is Hard on the Children
- Lack of Support from Medical Personnel
- Lack of Trust in HPs (re Info)
- Late Cancellations of Surgery caused Anxiety-Anger
- 'Leakage' of the Cancer
- Lingering Impairments Bother Me More Than Fear of Recurrence
- Lingering Impairments or SE Attract Unwanted Attention
- Lingering SE Not Bad Enough to Seek Help
- Living Appt to Appt Post-Treat with Uncertainty Over Cure (Timeline)
- Loathed Being in Hosp due to HPs Attitude to Smoking
- Lingering SE Remind Self of the Cancer-Lack of Normality
- Loss of Confidence
- Loss of Partner Post-Treat Devastating
- Loss of Time (Taken Up with Cancer-Treats)
- Loss of Appetite Post-Treatment (SE)
- 'Lucky' C Was Curable Despite Potential for Recurrence

M ----------

- Many of SE Experienced Due to Painkillers Rather than Ra
- Metaphors Aid Expression of Understanding
- 'More Difficult for People Around Me' (to Deal with My Cancer)

N ----------

- Nature of Follow-up Appointments
- Navy Experience Means Long-Aware of Mortality – This Helped
- Notice the Benefits Since Stopping Smoking
- Need to Weigh Up Safety (cure) v Impact on Life
- Negative Care Experiences (Lack of)
- Never Thought-Worried About How Cancer Kills
- Never Thought-Worried About Treats Damaging My Body
- Not Discussing Fears-Worries with HPs
- No Eating Problems and Put Weight on During Ra
- No Worries re Long-Term Chemo Effects
- No Worries re Long-Term Ra Effects
- Not Allowed to See Dentist-Hairdresser for Period Post-Treat
- Not Wanting to Impose Too Much on Supportive Friends
- Not Going to Worry About the Possibility of Recurrence
- Not Hiding It
- Not Telling People

O ----------

- Off Work but Looking after Self-Family is Hard Going
- One Nurse 'From Hell'
- Others' Need to Support Me

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- Others Reacting as if I Will Die 'Annoys' Me
- Others Triggered Little 'Niggles'-Worries Occasionally
- Own Image Represents All Cancer Despite Believing Diff Kinds

P ----------

- Pain Disrupts Sleep and Causes Tiredness
- Partner's Visual Description-Image of the Cancer
- Permanent Body Changes due to Ra
- Preconceptions – Ra Not as Bad as Chemo
- Pre-Diag Surgery on the Nodule
- Physical Impairments Have Got Worse
- Preconception – C Represented by Children-Elderly
- Patient-Partner Conflicting Perceptions
- PEG Feed 'Didn't Bother Me'
- PEG Feed was Awful
- Post-HNC – I'm No More Likely to get Cancer Again Than Anyone Else
- Positive Thinking
- Painful Symptoms 'Bring you Down'
- Positive Thinking Important (cure-control and so the body can heal)
- Partner has been Supportive
- People Consider Me 'Cured' just cause I've Finished Treatment
- Post-Treat – Discovery of a 'Polyp' at the Cancer Site
- Post-Treat – Feeling Physically and Emotionally a Good Bit Better
- Post-Treat – 'I'm Not Cured Yet' (won't know for 1-5 yrs)
- Preparatory Dental Work was a 'Nightmare'
- 'Putting on a Brave Face for the Kids' was Very Difficult
- Post-Ra – Addressing Dental Problems
- Post-Treat – Consider Self Cancer-Free Despite Uncertainty over whether C was Primary or a Secondary
- Post-Treat – 'It's Looking Good For Me'
- Post-Treat – Having 'Wet Days' of Frustration
- Post-Treat – Reluctant to Have Any More Major Treats Even to Correct Impairments
- Post-Treat – I am Back to Normal
- Post-Treat – Daily Life-Activities Back to Normal
- Post-Treat – Working Full-Time but Fewer Hours
- Post-Treatment I Will 'Get Back to Normal' Eventually
- Post-Treat Unsure if the Cancer is Gone
- Post-Treat Feel Others See Me as Well Now and Have to Conceal SE-'Be Normal'
- Preparing for Death
- Pro-Active Approach to Tackling Difficulties
- Prognosis
- Process to Diagnosis
- Protecting Others
- Proud of How I Coped with the Cancer-Treatments
- Proximity to Hosp Meant Ra Schedule Not Too 'Intrusive'

Q ----------

- Query Whether Previous 'Nodule' (5-10yrs ago) was Real Start of Cancer (Timeline)
- *Query whether Start of C was Previous Diag.-Benign Symptoms (Timeline-Identity)*

R ----------

- Radiotherapy is a 'Slog' (Tedious Daily Grind)
- Ra External Effects are Mirrored Internally
- Ra is – 'Like going on the Sunbeds'
- Ra Nature – Can be Harmful to You but Necessary
- Ra Schedule – Have had a High Dose
- Ra Means Lifelong Implications for Dental Care
- Ra Process Anxiety-Provoking (Worry it may go wrong)
- Ra Process was 'Disconcerting'-Difficult to Endure
- Relating the Diagnosis to Loved Ones – An 'Emotional Rollercoaster'
- Returning for Follow-Up Appts is Not Anxiety-Provoking
- Ra is like 'Black Magic'
- Ra Kills Good and Bad Cells But the Good Will Regenerate
- Ra Does – 'Just Kills It Off' (No Specific Action)
- Ra Mask Did Not Bother Me
- Ra Nature – Continues Working for Some Time After Finish Course
- Ra Schedule Intrusive Due to Travel Time
- Ra SE Not as Bad as Expected
- Ra SE Were Minimal (i.e. sailed through it)
- Ra Side Effects Come and Go in Waves Post-Treat
- Reaction to An Unexpected Turn for the Worse
- Recovery From Treatments Will Take a Long Time
- Recovery is Getting Back to Who I was Before (loss of self)
- Recurrence Location – Near the Carotid Artery
- Recurrence Symptoms-Process to Diagnosis
- Return to Work Was More Difficult Than Anticipated
- Reduction in Physical Symptoms Through Treatment is Reassuring
- Reaction to News of Post-Treat Operation
- Reassessing Life-Priorities
- Relief at Finishing Lengthy Treatment Schedule
- Reluctant Ever to Go Through the 'Hell' of

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Radiotherapy Again (should it be necessary)

- Return to Work is Important Marker of Return to Normality

S ----------

- Satisfied with Information have Received
- Side Effects from Morphine Pretty Bad
- Social Life Didn't Change Too Much
- Spread of Own Cancer was 'Normal' – Not as Significant-Scary as Other Kinds
- Support of Friends has been 'Fantastic'
- Satisfied with Treatments (Believe Positive Outcome)
- Satisfied HPs Prepared Me Well for SE Experienced
- Saw Post-Surgery Scoping Image of Site
- Shock at Diag Amplified as Told Site 'Pristine' 6 wks Previously
- Scan Images Contradict Own Conception of Where the Cancer Site Was
- Severity of Recurrence – Incurable
- Shingles was 'Worse Than Cancer'
- 'Shit Happens' – Cancer as an Event – Moving on Post-Treatment
- SE – Constantly 'Runny Nose' Irritates
- SE Really Kick in Post-Treat
- Services-HPs Negative – Unwillingness to be Flexible for the Patient
- Services-HPs Negative – No Urgency re Diagnosis-Treatment
- Stopping Smoking was Not Too Difficult for Me
- Stranger Reaction – Screamed when she Saw my Ra Burned Neck
- Surgery - Neck Dissection – Potential (not actual) Bodily Impairments are Serious
- Surgery Removed the Cancer But 'Broke' the Cyst
- Surgery – Visible Impact was Shocking
- Surgery was Scary as Knew it was 'Life-Threatening'
- Surgical Scar Not Very Noticeable to Others
- Sickness-Nausea (Treats Impact)
- Sleep Difficulties
- 'Sleeping Through the Worst of It' (Coping With SE)
- Sleep loss through worry
- Some HPs Better Than Others
- Still Find it 'Unreal' (hard to believe) That I Had Cancer
- Striving-Desire to Regain Weight Post-Treat
- Struggle to Avoid Stress
- Struggle to Keep Neg Thoughts Away
- Struggle to Perform Self-Care Activities
- Struggle to Seek Help with Depression (Feelings about Dying)
- Struggle to Stop Smoking
- Struggle with Depression Post-Treat (Good and Bad Days)

T ----------

- Taking Control
- Tedium of Persevering Through Eating Problems – 'Fed Up'
- Telling Children
- Taste Loss is a Big Loss
- The Importance of Early Detection
- Treatments So Debilitating You 'Feel Like An Old Man'
- The Toll of Months of Fatigue
- The 'Bore' of Lengthy Treatments
- Tiredness-Fatigue is 'Worst Part' of the Experience
- Tissue Damaged By Ra Will Heal (Internal and External)
- Transport Issues
- Treatment Timeline
- *Treatment Extent-Impact Greater than Imagined*
- Treatments as a Necessary Evil
- Treatment SE Not As Bad As Expected
- Treatments caused worse symptoms than the Cancer
- Treatments Take Over Your Life
- *Treatments Post-Surgery are Precautionary*
- Trust HPs Know What They're Doing So No Need to Seek Info
- Try and Think of All Cancers as Contained (Imagery Coping)

U ----------

- *Uncertainty Over-Fear of Recurrence*
- Uncertainty Over How Well Body Will Recover from SE (maybe not fully)
- Unexpected Benefit from SE – Will Now Get Teeth Fixed
- Unidentified Symptoms Don't Worry Me for Long as Believe if is Painful is Not Cancer
- Unsure of Value-Efficacy of Follow-Up Appts as C Eluded Detection Last Time
- Unquestioning Compliance
- Unsure How a Recurrence Would Manifest-Occur
- Unsure How Chemo Identifies the C-But Assumes it Does
- Unsure Whether Recurrence is New Cancer or Part of Initial One

V ----------

- Value of Accessible Support
- *Voice-Box Removal (if it became necessary) 'Can be Overcome'*
- Voice is Changed Post-Treatment

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- Voice Rougher Means Dislike Talking on Phone

W ----------

- Waiting to Die – Boredom, Depression, and Suicidal Thoughts
- Weight Loss
- What Happens to the Cancer After Treatment
- What Is Fighting Cancer
- What the Cancer Looks Like is Not Important to Me
- When Will Lingering Side Effects Clear
- 'Wherewithal to Get Better was Harder When You Couldn't Eat'
- Will Be An Adjustment Getting Back to Work
- With Hindsight HPs did not Explain Treats-Options Fully Enough
- Won't Know If Am Cured til End of 5 Years – 'In Limbo'
- Work Have Been Supportive
- Worry About Ra SE – Expect to be Awful
- Worry About the Making of the Ra Mask
- Worry Over Damage from Chemo
- Worry Over Secondary Infections-Other Complications due to Treatments
- Worry the Surgery May Kill Me
- Worst Thing about the Follow-Up Appts is the Scoping
- Would Go Through the Treatments Again – 'Too Much to Lose'
- Would Not Go Through the Treatments Again

Y ----------

- 'You Have No Control Over Your Life' – When Have Cancer
- 'You're Just An Illness' – Defined by the C
- 'Your Dignity's Stripped Away When You Walk in the Door' (Being in Hosp)

TREE NODES

+ C BEHAVIOUR (ACTION)

'Attacks' the Body (c action)

Cells Multiply Progressively (c action)

Don't Necessarily Feel It Doing Anything (c action)

'Eating Away' (c action)

'Festering' (c action)

Growing (c action)

'Takes Over' Tissues (c action)

Unsure What Cancer Does (c action)

+ C DOES… (Identity-Physical Action-Consequences=Bodily)

- Can Be Asymptomatic (c does)
- Can Affect Functioning of Other Parts of the Body (c does)
- Can 'Store Itself' and Appear a Long Time After it Was Caused (c does)
- Causes Pain (c does)
- Doesn't Affect the Rest of the Body (c does)
- May Cause Tiredness (c does)
- Query Triggers a Reaction in Cells Before Infecting Them (i.e. Causes Swelling) (c does)
- Tricks the Body to Avoid Attack (c does)
- Tumours Can Bleed (c does)

+ C IMAGERY

Anatomical Location – On or Inside

Behavioural Imagery

Can't Describe It as Don't Know What a Cancer Cell Looks Like

Colour

'Dead' Cancer

Different Bits of Own Cancer Look Different

Differs Visually per Site

Feelings About the Image

Have Not Thought About What It Looks Like

Image of Some Parts of Cancer and Not Others

Invisible Cancer

Metaphorical Visual Description of the Cancer

Never Thought About if it Differs Visually Per Site

'No Image Of It'

Other Cancer

Perceived Origins of Images

Size Matters

'The Cancer'

- Visual Description of the Cancer (Not a Concrete Image)

Visible Cancer

+ C IN SOCIETY

- A Taboo Subject
- Frightening to Some People
- Media speculates on numerous C causes

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- More Accepted These Days
- Others' Perceptions of C
- Stigma
- Telling People-Others' Reactions
- The Word = Death
- Breast C Much More Publicised

+ C IS… (Identity)

+ AS A DISEASE (Nature-Identity)
- An Illness Like Any Other
- A Common Disease
- \\\A Progressive Disease
- A Virulent, Serious Disease
- Not Contagious
- The 'Character' of Cancer
- There are Various Different Kinds of Cancer

+ PHYSICALLY (Identity)
- Abnormal – Not Part of Own Body
- A Cellular Disease
- A Growth
- A Mass
- A Swelling
- A Tumour
- A Wastage
- A Mutation of Own Body Cells
- Corrupt DNA
- Like A Poison
- Part of Own Body
- Unsure What C Is
- Unsure whether C is Part of Own Body or Not

+ C IS AN UNKNOWN QUANTITY (PRIOR KNOWLEDGE)
- C Always Represented by Lung Cancer
- C is Not Thought of Til It Happens
- Experience is a Huge Learning Curve
- Treatments are an Unknown Quantity

+ C LOCATION (Identity)
- 'Bits' of Cancer
- Lymph Nodes
- Jaw Bone
- Neck
- Nasopharynx
- Oral Cavity
- Spine
- Throat or Larynx
- Unknown or Unconfirmed Location

+ C REACTION

+ TO DIAGNOSIS
- Acceptance
- Anger
- Concern for Business
- Concern for Partner-Family
- Confirmed Own Belief Had C
- Denial
- Fear of Death
- Felt Numb
- Forewarning 'Helped to Make it Easier'
- 'I'll Beat It'
- Relief
- Sadness
- Shock
- Uncertainty
- Wanted to Get Out of There
- What Do We Do About It (*This is not a new node but was not here – when created?)

+ TO SUSPICION
- Wait and See
- Denial

+ C SEVERITY

+ OF CANCER IN GENERAL:
- Always Appears Serious on TV
- Highly Variable
- Is a Treatable Disease
- Potentially 'Deadly'

+ OF OWN CANCER:
- A 'Minor' Cancer
- 'Aggressive' [DELETED: 'Thus Needing Aggressive Treatments']
- Caught Early
- HNC 'Less Serious' Than Organ Cancers
- Inoperable or Incurable
- More Symptoms = More Serious
- Serious But Treatable
- Size Indicates Severity
- Spreading = More Serious

+ C SPREADING

+ NATURE OF SPREADING
- Can produce 'secondary' cancers
- HNCs Spread Locally Usually (ie. Rather Than Into the Body
- HNC Spreads Downwards, Not Up

+ MECHANISM OF SPREAD
- Cancer 'Latches On' and Destroys

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- Physical Contact or Closeness
- Physically Dislodged
- Spread is a Mystery
- Surgery Could Cause
- Through the Bloodstream
- *Through the Bones*
- Via 'Lymphs'
- Via A Range of Techniques
- Via Continual Growth (i.e. joined up)

+ CAUSES OF OWN HNC

- Bad Luck-Chance
- Can Affect Unlikely Candidates
- Don't Know The Cause
- Knowing the Cause is Important
- Not Thought a Lot About the Cause
- Recurrence of Previous Cancer
- The 'Conditions' Have to Be Right for it to Develop
- What is Not the Cause

+ BODILY OR BIOLOGICAL FACTORS:

- Age is a Factor
- Injury
- Is Cancer Always There and Suddenly Is Triggered
- Query a Genetic Predisposition
- Query Medication
- Query Physical Ill-Health at the Site

+ ENVIRONMENTAL OR LIFESTYLE FACTORS:

- A High-Sugar Diet
- An 'External Agent' Causes Cells to Mutate
- Asbestos-Cement Water Pipes
- Querying Other Potential Lifestyle Causes
- Smoking and-or Drinking
- Smoking-Cheap Tobacco
- 'Something I've Contracted'
- Stress

+ CHEMOTHERAPY

- Ch Action - 'Shrinks' the Cancer
- Ch Aim-Purpose
- Ch Current SE
- Ch Expected SE
- Ch Timeline – Sessions-Duration
- Ch Worries
- Side Effects-Impact of Chemo

+ CH DOES:

- Ch Does – 'Drains the Potassium'
- Ch Does – Kills Cancer Cells – But Why Not All
- Ch Does – 'Kills Fast-Developing Cells'
- Ch Does – Kills Cancer Cells and Good Cells

+ CH IMAGERY:

- Ch Imagery – 'Dead' Cancer Cells are Flushed Out Through the Kidneys
- Ch Imagery – 'Latches Onto' Cells and 'Stimulates Them to Death'
- Ch Imagery – 'Shrinks' the Cancer-Cells
- Ch Imagery – 'Swallowing Up' the Cancer Cells

+ CH IS:

- Ch Is – Contains Platinum
- Ch Is – Drugs in Fluid Form
- Ch Is-Nature – 'Poisoning'
- Ch Is – Toxic Chemicals

+ CH NATURE:

- Ch Nature – Administered Along With Fluids
- Ch Nature – Circulates Through the Whole Body
- Ch Nature – Continues to Work for a Period Post-Administration
- Ch Nature – Damages Kidneys if Not Flushed Out the System
- Ch Nature – Goes in to the Heart and then is 'Fired to the Tumour'
- Ch Nature – Impairs Immunity
- Ch Nature – Kills Good Cells But These Will Regenerate

+ CONSEQUENCES

+ CONSEQ. OF C AS A DISEASE:

- Can Be Fatal
- Can Cause a Slow, Painful Death
- If Untreated – Bodily Consequences
- Loss of Independence Before Death (when terminal)
- When Fatal Causes a Slow, Progressive Deterioration

+ CONSEQ. POST-TREAT BODILY:

- Body Weakened Post-Treatment
- Heightened Sensitivity to Sun Post-Ra and Ch
- Site of the Cancer 'Feels' Different
- Site of the Cancer will be Slightly Changed
- Site of the Cancer Will Return to its Pre-Cancer State
- Surgical Changes Will Heal in Time
- The Body Will Regenerate
- There Will Be No Lasting Damage from the Radiotherapy

- **+ COPING**
- Acceptance & Positivity
- Always someone worse off
- Avoidance

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- Dealing With It As It Happens
- Embracing Self-Care
- Faith in Own Mind & Body
- Faith in HPs
- Family = Motivation to Get Well and Carry On
- Fatalism
- Finding Practical Solutions to Ease Comfort
- Focussing on What is Known and Not What May Happen
- Focussing on Treatment
- Getting on with it
- Having Goals
- Humour
- Keeping Busy
- Keeping it to Yourself
- Limiting Information for Self
- Looking after Own Emotions
- Maintaining Some Normalcy
- Not Thinking Too Much About the Cancer
- Not thinking too Much about the Treatments
- Religious Faith
- Reminding Self is a Temporary Situation
- Support from Others
- Visual Mental Relaxation

+ CURE-CONTROL

- Can Positive Thinking Help
- Compliance with HPs
- Curable By Radiotherapy
- Cure is in the Hands of HPs
- Positive Attitude & Action
- Progression Can Be Slowed
- Removable by surgery
- Recurrence is Out-with Control
- Responsibility to Keep Self Well
- Stopping Smoking
- Stress is Counterproductive
- Strong Mind & Strong Body = Better Chance of Survival
- Survival Completely Out-with Own Control

+ DETECTING CANCER

- By Affected Lymph Glands
- Can Elude Detection
- Can Be Seen By HPs
- In blood
- Through Biopsies
- Through Scans – CT, MRI, PET etc

+ FEAR-UNCERTAINTY-UNPREDICTABILITY OF THE EXPERIENCE

- The Hell of Waiting
- Unanticipated Symptoms Cause Fear-Distress
- Uncertainty – C Can Spread or Worsen At Any Time
- Uncertainty-the Unknown Causes Fear-Anxiety
- Uncertainty – Experience is 'Uncharted Territories' and You Have No 'Frame of Reference'
- Uncertainty Over Future Means Can't Make Long-Term Plans
- Uncertainty Over How the Cancer Will Progress (Incurable)
- Uncertainty-Fear Over Long-Term Implications of Treats (Possible Impairments)
- Uncertainty Over the Possibility of Further Treatment
- Uncertainty Over How Long I Have Left (Incurable)
- Uncertainty – Whether Treats Will Improve QoL
- Unpredictability of Side Effects-'A Real Rollercoaster Ride' Emotionally
- Will I Get Back To Who I Was Before
- Will Impairments Be Permanent (Uncertainty)
- Worry Over Treatment Efficacy

+ HEALTH CARE EXPERIENCES

- Good Co-Patient Env on Wards
- Hospital Env is Positive-Helpful
- Hospital Env (environment) reinforces illness
- Hospital Env is upsetting
- Not much contact with High HPs
- Services-Treatment Positive

+ HNC CAUSES IN GENERAL

- Smoking and-or Drinking
- Smoky-Dusty Work Environment

+ HPs NEGATIVE

- Appointment-Organisation Difficulties
- Delay in Procedures
- Delayed Diagnosis
- Feeling 'Forgotten' in Hospital
- Feeling Misled
- Inaccessibility
- Insensitivity
- Lack of Clinical Skills
- Lack of Information
- Lack of Personal Attention

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- Mismanaged-Confused Diagnosis
- No Relationship with Carers-Families
- Not Being Listened To
- Poor Information Giving-Discussion

+ HPs POSITIVE

- Confidence in HPs abilities
- Good relationships-Likeable
- Honest direct approach
- HPs Have Been Supportive
- Speed and efficiency
- Taking the Time to Explain Things
- Well Organised

+ IMAGERY EXPOSURE

- A Diagram Suffices
- Desire to See the Cancer
- Had Scans But Did Not See Them
- Had Photos of the Cancer Taken
- HPs' Visual Descriptions of the Cancer
- Images of the Cancer as Upsetting
- No Desire to See Scans etc (this node not new but was not listed here – when created?)
- Not Wanting to See The Cancer
- Never seen scoping images
- Public Health Poster
- Radiotherapy Info Booklet
- Saw Photo of Own Cancer
- Shown Before and After Surgery Images
- Shown Drawings
- Shown Scan Image
- Shown Scoping Image

+ IMPACT OF CANCER ON MY LIFE (CONSEQUENCES)

A Temporary Disruption-Affliction (Identity-Timeline)

Affects Self-Image

- Cancer Hasn't Changed My Life
- Causes Pain
- Changing Body Image
- Daily routine is disturbed
- Diet Changes
- Disruption to Plans-Life on Hold
- Eating Impairment
- Eating Problems Disrupt Life
- 'HNC is the Most Antisocial Cancer'
- Impairs Breathing
- Interrupted Work Life
- 'It's Never Completely Gone' – Follow-ups (Timeline)
- Lack of Normality
- Life Doesn't Stop Cause You Have Cancer
- Living a Healthier Lifestyle
- 'Living Day to Day' in Face of Uncertainty
- Needing Help
- Physical Impairments Disrupt
- Sex Life on Pause During Debilitating Treatment
- Shame-Embarrassment of Physical Dysfunction
- Social Isolation
- Speaking Impairment
- Tiredness

+ IMPACT OF TREATMENTS ON MY LIFE

- Difficulty Speaking (Treats Impact)
- Dryness of Mouth-Throat (Treats Impact)
- Eating Difficulties (Treats Impact)
- Hair Loss (Treats Impact)
- Meal Times are No Longer Fun (Treats Impact)
- Pain (Treats Impact) *[Deleted -'in the Mouth']*
- Social Isolation (Treats Impact)
- Taste Changes (Treats Impact)
- Thick Mucous in Throat (Treats Impact)
- Tiredness (Treats Impact)

+ INFORMATION

- Can Be Overwhelming (A Lot to Take In)
- Desire to Understand What's Going On
- Difficult to Ask Questions
- Difficult to Take in Info
- Have To Be Assertive To Ask Questions
- HPs Cannot Always Provide Exact Info Desired
- HPs Pre-Warning of Side Effects is Reassuring
- HPs Talk About But Not To You
- Limiting Self to Reliable Sources
- Misunderstanding Info
- Seeking Out Desired Info for Self
- Self-Interpretation of Info Leads to Distress

+ OTHER CANCERS ARE CAUSED BY

- Age is a Factor
- Alcohol
- Asbestos
- Bad Luck-Chance
- Can Affect Unlikely Candidates
- Carcinogenic Substances

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- Child-bearing, Sex Life
- Don't Know the Cause
- Genes-Hereditary
- Maybe Cancer is Always There and Suddenly is Triggered
- Radio = Heightened Sun Sensitivity-Skin Cancers
- Smoking
- Stress
- Sun Exposure
- The 'Conditions' Need to be Right
- Viruses

+ RADIOTHERAPY

- Ra Aim-Purpose
- Ra Current SE
- Ra Expected SE
- Ra Timeline – Sessions-Duration
- Ra Worries
- Side Effects-Impact of Radio

+ RA ACTION:

- Ra Action – 'Blasts Rays'
- Ra Action – 'Burning'
- Ra Action – 'Scraping'
- Ra Action – 'Zaps' the Cancer

+ RA IMAGERY:

- Ra Imagery – Action – Blasts Rays
- Ra Imagery – Action – Burns the Cancer
- Ra Imagery – Action – 'Zaps' the Cancer
- Ra Imagery – Born of Gaps in Understanding
- Ra Imagery – Does – Scrapes Away the Tissues
- Ra Imagery – Does – Shrinks the Cancer
- Ra Imagery – Is – Beams or A Laser or Laser Beams
- Ra Imagery – Is – Like Sticking Your Head in a Microwave
- Ra Imagery – It's Not 'Space Invaders'
- Ra Imagery – Nature – Gun-related eg. 'shoot' or 'fire' it
- Ra Imagery – Works 'Like a Laser Gun'
- Ra Works Like a High Pressure Water Jet (imagery)

+ RA IS:

- Ra Is – 'A Laser'
- Ra Is – 'Beams'
- Ra Is – Like a 'Chemical Peel'
- Ra Is – 'Like Sticking Your Head in a Microwave'
- Ra Is - Radiation
- Ra Is – 'Radio Waves'
- Ra Is – 'Rays'
- Ra Is – 'X-Rays'

+ RA NATURE:

- Ra Nature – Accumulative
- Ra Nature – Body Can Only Tolerate a Finite Amount
- Ra Nature – Painless During Administration
- Ra Nature – Takes Time to Work
- Ra Nature – Targetted to a Specific Area

+ THE RA MASK:

- Ra Mask Has a 'Gap' for the Ra to Enter
- Ra Mask is Unpleasant – 'Like Having Your Head Mummified'
- Ra Mask Purpose – Protection
- Ra Mask Purpose – To Ensure Position

+ SURGERY

- Impact of Surgery
- *Outcome of Surgery – Did Not Remove All the Cancer*
- *Post-Surgery required Scar Excision due to 'Contamination'*
- *Risks of Impairments after Surgery were Significant-Frightening*
- Surgery Aim-Purpose

+ SURGERY IS:

- *Neck Dissection (removal of lymph nodes, tissues etc)*
- *Preparatory Work – Biopsies, PEG Tube Insertion, etc*
- *Removal of Cyst (Pre-diagnosis)*
- *Removal of Growth-Tissue the Cancer was In ('Cut off' or 'Cut out')*
- *Removal of Lymph Glands-Nodes*
- *Removal of Tonsils*
- Surgical Imagery
- Surgery SE
- Surgery Timeline-Duration
- Surgery Worries

+ THE NATURE OF TREATMENTS

- Outcomes Cannot Be Guaranteed
- Side Effects Vary Between Individuals
- Treatments Are Brutal
- Treatments Are Much More Advanced Than They Once Were
- Treatments are Specific to the Individual
- Treatments Damage Non-Cancer Tissues
- Treatments will Tackle All Bits of Cancer in the Body

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PATIENT: [redacted] DIAGNOSIS: Oral cancer + 2x "infected" lymph nodes. TREATMENTS: Surgery, Chemo + radio CONFIDENTIAL

PART 1 – CANCER

A) BELIEFS ABOUT CANCER:

(* "knew it didn't look right" + expected something serious like cancer)

Identity:

- First symptoms — like a mouth ulcer or abscess ("bump") appeared above wisdom tooth at top (R) side back of mouth. V. painful. Dentist gave penicillin for swelling. Then it "semi-collapsed" + appeared like a "lesion" + he realised it wasn't a normal abscess*. Tooth extracted (v. loose) then swelling ("white truffle") where it had been. Dentist referred → A+E → [redacted] Clinic + told 99% chance cancer.
- Nature — Needs "a host", "latches on to something" + sets up camp + spreads out from there. Is part of own body ("rogue cells") which goes bad, but not everyone develops it.
- What cancer is — Shock + focus on treatment.
- Diagnosis — To do with changes in the cells – "any change is a potential problem cell" – "every division could be faulty". Cells breaking down is a natural process + that's why more older people get cancer as the cells "deteriorate".

Various kinds – his rarer than lung Ca.

Is a common disease + no different he feels to any other illness.

Feels his prognosis is "good" + he's comparatively well + statistically it's "one of the better cancers to get".

Cause:

- General cancers — Poor diet, smoking, sunlight.
- Own cancer — Bad luck = happened in spite of living a healthy lifestyle (good diet, not smoking (quit), no alcohol since drug-use (IV)).
  - ↳ No other causes he can identify, just "unlucky".
  - Doesn't know why it developed where it did, queries a "weakness" there or a proneness.

Consequences:

- Action — "Growing". Thinks they (cancer cells) "push" "more active or stimulated more or to do diff things" than normal cells. Takes over + "jumps onto" surrounding tissues as it spreads: "like a truffle".
- Spreading — has "infected the lymphs" (2 of 5). It's "bad news" when it gets into lymph system. Diff ways of spreading + manages to "disguise" it self to stop the body getting rid of it – it "tricks" the body that it's not bad cells.
  - If untreated the C would spread, continually growing, spread through the body + kill you.
- Other — His C is the most "antisocial one" as "your face is who you are basically". (* bright clinical signals it present)

It "casts off" cells to spread

Some normality will come when he gets functioning back.

Timeline:

- Beginning — has been there longer than HP's first thought to "get so "extensive" + have infected the lymphs, first sign he had "was just it bursting out", so he'd had it for some time before this. (in above the jaw bone)
- Duration — Follow-ups over years so it's "never completely gone".
- End? — Hopes to "look back on it" and it'll all be a distant memory", and his side-effects will be v. much improved.
  - Will feel more himself when he's able to eat + speak normally again.
  - Lots of anxiety re the future – how much functioning he'll regain, if the cancer will return, etc.

But his body will be forever changed (bits missing) due to surgery.

(Cancer/it is not all joined up) + can get into blood stream/lymph system + travel to lungs etc.)

Cure/control:

- Treatments — hopeful of cure, feels prognosis is good.
- Self — looking after himself + staying healthy - eating well, not smoking (quit years ago), not drinking (hasn't since diag.) — to give just the treatment best chance of working.

B) IMAGERY: Origins of Imagery: knowledge of muscle/st tissues - needs a blood supply, just the same.

- Shape
- Size
- Texture — "like a sausage without a skin with lots of blood vessels ... just a mass" - Has got a v. good blood supply. - But he could see it like a sausage with a skin as it reads the coating (comes white colour) (* "atmosphere or from the saline and stuff", inside it would be healthy-coloured, a "mass of blood vessels.")
- Colour
- Composed of
- Location — Visible part of cancer - located where wisdom tooth extracted - like a "white truffle" - "a small lumpy, like a dried mushroomy" thing. - Balloons inside it would look a bit different (no white coating) more "blood vesselly" + without the hard coating it needs to "protect itself" from the*
- HPs' descriptions — The cancer was "bigger" than the surgeon first thought - how it appeared on the MRI = it was "all growth" whereas sometimes the MRI can show up fluid which makes the cancer appear larger (this was not the case).
- Exposure to images — Would've been interested as quite interested in stuff like that.
- Drawing produced — No, he declined. Preferred me to look at the photos of it in his file. Felt also he'd be unable to.
- Patient's verbal descriptions

(* HP explained showing a "slice" of MRI + * where the radiographers scan and process but not discussed them with HPs. Photos taken of it at the hospital + he caught a glimpse of these. ** if it's all internal (eg lung) it wouldn't need the skin + would be like sausage without. No feelings of disgust etc - focus was on pain.)

- Unsure whether C would look the same wherever it was or if it'd be different, eg. "across a kidney just sort of die and sort of shrivel up".
- Thinks a lot of cancers "seems to go all black and dry up basically + things don't work", whereas his + lung, mouth + tongue cancer is "quite bulbous sort of growth" (in rather than internal the growth is protruding).

PATIENT: DIAGNOSIS: TREATMENTS: CONFIDENTIAL

(*This hole will be covered with graft from hand next year (August) but potential probs as his veins in hands are not totally correct so could compromise his hand)

PART 2 – TREATMENTS — Originally thought all that would be needed is to have it cut out like a mole.

A) SURGERY — Carried out 2wks post-biopsy.

- Action — Removed lymph nodes, chunk of gum, chunk jaw bone + "all the muscle + stuff" on inside of cheek, up to beneath the ear. Removed some of the hard palate + sinuses.
- Outcome re cancer
- Outcome on body — Has lost some of his breath.
  - The surgery was more "drastic" than anticipated – they removed a lot more than he expected.
  - A "hole" beneath the ear + where the bits of hard palate + sinuses removed (roof of mouth).
- Imagery
- Side effects — voice has changed (bit nasal) due to hole + plate in mouth.
  - mouth opening v. restricted = chewing + eating compromised. Plate to cover hole in roof of mouth must be removed + cleaned after eat*. Lack sensation top (R) side, bottom lip, chin to windpipe. (R) side face, jaw + throat is numb. Pins + needles in area.
  - → this has improved some but unsure if it will totally.

surgeon said he had to stop going up towards ear as he was "hitting arteries + stuff which would compromise a lot of stuff." ↓ the cancer was "bigger" than the surgeon thought + so they were keen to do ch + ra as a precaution as they couldn't "get up quite as far as he wanted to do".

B) RADIOTHERAPY — Purpose as per chemo ("mopping up")

- Process — Mask (claustrophobic), can't feel anything. Targeted to 3 areas.
- Action
- Outcome — "destroys cells" – can't see it, it's like light – it's just there, they're "high energy particles". Once the cells are dead the body deals with them via liver / blood / white cells / lymph nodes as it does with all bodily wastes.
- Current side effects — *nos "sailed through it" so far, apart from 2 days ago tongue + gum started ulcerating (due to combo ch + ra).
- Expected side effects
- Imagery

- Nature – "high energy x-rays" – v. damaging to healthy cells also.

PATIENT: **DIAGNOSIS:** **TREATMENTS:** **CONFIDENTIAL**

More unsure of this.

C) CHEMOTHERAPY – Purpose to "mop up" anything he'd missed during surgery + precautionary. [Action too]

Takes 6+ hrs - is pumped into a vein

- Process – salt water, fluids, chemo, fluid bags.
- Action – [redacted] • Nature – is a platinum based drug "Sysplatin". Thinks it might "catalyse" + "stimulate" them to death as platinum is a catalyst.
- Outcome – is a "chemical reaction" is in your blood. Intends to ask HPs more re this as doesn't know much about how it works. Doesn't know how the chemo can identify the cancer cells they, but thinks they must be different to normal cells "buster" + they "grab onto" the chemo quicker than normal cells + it queers it (worry) + damages them. "Just stimulates them to death."
- Current side effects
- Expected side effects – is bad for the kidneys - it can "settle there" – so you get lots fluids with the chemo to "flush your kidneys out".
- Imagery

PART 3 – OTHER FIRST-INTERVIEW ASPECTS TO FOLLOW UP ON

- Pertinent features of their HNC experience – eating probs far worse than anticipated + it wasn't explained adequately he feels. – limited in what can eat + has to plan everything (no spontaneity).
  - "Eating is one of the biggest hardships" – cos chewing so restricted, difficult + painful. And food's "always where..." it's a social thing, it's a family thing". It is no longer pleasurable, chewing is a chore". Must eat soft food in tiny bites cos so it doesn't burn HPs. Is using a machine to try + stretch the scar tissue but at night it "goes back to square one" + he's just as restricted. Cos eating = ordeal does it mean does.
  - All the side effects of the treatments are a lot to take at once.
- Previous experience of cancer
  - Mother died of C 20yrs ago but this "never even crossing mind" + didn't influence his reaction to it as circumstances "totally different".
  - Not angry re delayed diag. re chemo
  - Spreading is a worry + if it's anywhere else in his body.
- Coping
  - Always someone worse off (older patients, glad he is young enough to endure tough treats).
  - Feels he "has to get on with it" (has good + bad days).
  - Focus on treat. + faith in HPs.

- Treatments started v. quick post-diag + this pleased him.
- Some insensitivity from HPs re re mask making.
- Has adapted to new "regime" of re + ch schedule.

- Changed self-image due to physical disfigurement, "frozen" face, difficulty speaking = feels like a "freak".
- Self-conscious re voice change + 15/04/2009
- Avoids talking when possible (also worries people will think he's brain-damaged)
- Feels defined by his illness (became very upset re this)
  "you're just a cancer patient" (loss of self)

PATIENT: [redacted] DIAGNOSIS: Neck Cancer TREATMENTS: Palliative cycles chemo + radio CONFIDENTIAL

Interview 1 = 1 wk in to chemo

Because it started to get bigger she thought "cancer"

PART 1 – CANCER

+ went to GP (approx 2 wks after it appeared)

A) BELIEFS ABOUT CANCER:

Identity:

- First symptoms — (approx 10wks prior to Int.) Pin believed it was cancer right from the start. [redacted] "something in me was telling me it was cancer") but 1st doctor disagreed + said it was an abscess. + scan, lump on neck growing slowly bigger 1st doctor (Hereford) drained it as thought was abscess → biopsy + told it was cancer → 2nd biopsy (Dundee) → terminal cancer.
- Nature — Various types + degrees of severity + "it is a disease that can be cured or can't be cured"
- What cancer is — is something which has come from her own body. Normal tissue which has been damaged. "Abnormal" tissue.
- Diagnosis — inoperable, terminal cancer in the neck. Was "surprised" at diag. as initial was told it's not cancer, then it might be C but is operable, then "told point blank it is inoperable, it's terminal" (All that in the space of 3 wks).

Cause: Went to see GP after had had lump for a couple of wks + it was growing slowly.

- General cancers (Breast-having kids increases risk; cervical + sex increases risk;)
- Own cancer — Own healthy tissue becomes abnormal – queries whether "outside influences" do this + whether "smoking has kind of" Smoking (own belief – no-one has suggested this) but "it could be any number of things". Has been a "heavy smoker all my life". "Luck of the draw"; Queries if we all have a "cancer gene" in us + it develops in some + not others. Also believes smoking likely for neck as is close to it.

Consequences:

- Action — ~~Worrying about it~~ "Festering and rotten" inside the lump. Growing in its own space (not affecting other tissues which are healthy enough, is not eating away) "but that's only my imagination"
- Progress of disease: ~~Spreading~~ — Worries it may affect her eyesight, may spread to her brain (knows she gets a headache), + may affect her mental ability**
- Other — Eating + breathing problems due to its location* can feel a lump at back of throat impeding + has been living on porridge + jelly mainly. Pain (on many painkillers round the clock). Death from cancer is painful so Problems with thick mucous in throat (need to confirm C is cause of this T2) she will kill herself

Timeline:

- Beginning — lump appeared in neck
- Duration — incurable
- End? — death. AP said some people can live up to 3 yrs but is best to begin treat. immediately

Death-her cancer is terminal (mechanism? T2) ↓ hasn't got a timeframe yet – it "depends on how my body copes"

(**The worry is mental ability is esp. bad as "when do you know the right time to end it" – she plans to kill herself + has to beware of "losing the plot".)

(*Has lost a stone in the past month due to inability to eat)

(*opened it up to outside influences and then the outside influences have come to develop the cancer.")

cont top 19.

Cure/control:

- Treatments — Cannot cure it but can "kill it off" as much as possible to give her more time.
- Self (& HPs told her) — it didn't have treat. said he'd be in pain* - she happy to do it as long as it's not constant til she diss (which they explained it wouldn't be, they'll: "get it as small as possible and then leave me alone."

B) IMAGERY:

- Shape — wimpy with "all veins through it and everything"
- Size
- Texture — "puss"
- Colour — "red and pussy", "...because it's to do with your veins and bloods... like an open wound, you'd expect it to be red" (colour origin - poster + knowledge of body)
- Composed of
- Location — mouth.
- HPs' descriptions
- Exposure to images — says she saw this image on a cancer poster in the doctor's surgery after her diag: "I saw that and thought oh that's what it is." This is the origin of it.
- Drawing produced — Yes - reproduces the poster
- Patient's verbal descriptions

-impact of the image = "It looked a bit yuck, looked a bit horrible". (Explore this more T2) ↓ (Query - disgust)

+ final cancer part of the swelling in her mouth/throat.

Has had a CT scan but has never seen it nor any other diagrams → says it's maybe for the best that she's not seen it: "I don't know whether it's best left to the imagination or reality, I am not sure". (Perhaps frightening reality? - T2)

PART 2 – TREATMENTS

A) SURGERY

- Action
- Outcome re cancer
- Outcome on body
- Imagery

} N/A - her cancer is inoperable.
She says the only explanation HPs have given her is that: [redacted] "it was just too far gone".

B) RADIOTHERAPY – Has not started this yet + has not been told much about it at T1.

- Process
- Action — "blast it with radiotherapy" — says has no idea how it acts on the cancer.
- Outcome — "just to try and kill it as much as possible"
- Current side effects — N/A
- Expected side effects
- Imagery

- "The only thing I've been told is if they go too hard sometimes it can burn you" - believes burning is due to too high a dose, not a normal side effect.

- Nursed her partner til her death (suicide) but can't say if she was still alive whether it'd make her feel differently re the cancer → possibly but it's all hypothetical so hard to say.

*she was angry they didn't take her seriously at the start as she's "pretty sensible... not prone to... screaming!"

PATIENT: **DIAGNOSIS:** **TREATMENTS:** **CONFIDENTIAL**

C) CHEMOTHERAPY — Had problems using the pump at first - the balloon wasn't moving at all + rang hosp. - they put her off 2 x 24hrs + eventually realised it was blocked + 2/3 went in in 24hrs*

- Process — Chemo (in for 1 night + then home with the pump). 5 days chemo → 3 wk break, 5 days → 3 wk break, 5 days chemo → then after will start the radiotherapy.
- Action — Will "shrink" the cancer (unsure if this my or PM-prior to taping-phrasing=check this T2). The lump has decreased
- Outcome — some in size already. "to kill it as much as possible" - "to shrink it".
- Current side effects — No ill-effects at T1 other than tiredness ("takes a lot of energy out of me").
- Expected side effects — Unsure, but knows it affects people in different ways - maybe hair loss, sickness, diarrhoea/constipation.
- Imagery

says she has no idea of its action on the cancer, all she knows is it's "pumping chemicals through your body".

PART 3 – OTHER FIRST-INTERVIEW ASPECTS TO FOLLOW UP ON

- Pertinent features of their HNC experience
  - Mentions "try and drink as much as I can" during chemo - why? (T2 Q)
  - Has accepted she's dying but her mother clings to false hope.
- Previous experience of cancer — None, nobody close to her

- Had been trying to commit suicide before the cancer (prior to and since the loss of her partner). Claims she is: "not actually suicidal now. I hardly feel it now... [but re the cancer] I'll take my own life, when it gets bad enough".
- Says death doesn't scare her, but she doesn't want a painful death.
- Is considering going to Maggies for relaxation etc.

- Coping
  - Says she hasn't been told in massive detail about the cancer, but trust HPs to tell her what she needs to know.
  - Acceptance - "it's pointless thinking about it, it's happening".
  - Avoidance - trying not to think about it + keeping mind occupied by reading as: "it's not going to achieve anything, you know, it's not going to make it go away".

- Family have been v. supportive but she prefers to be as independent as possible - eg. driving self to hosp when possible.
- Reports some emotional 'numbness':
  - "...nothing I can do about it at all. I can't, I just don't feel anything".
  - Says in the "wee small hours" when she thinks of it she feels "empty" but "can't really put an emotion on it".

Otherwise has good relats with HPs at NNU "couldn't fault them"

+HPs negative:
- Disbelief at chemo pump problems
- Cocked up by saying 1st - it's not C, 2nd - it's C but operable, then 3rd - it's C + terminal. She'd rather they had: "shut up until they know for sure and then tell you", as "it was a bit of a jump" to be told all that in 3 wks.
- One of the NNU docs said he wasn't happy they'd cut into the lump to drain it (thinking it was an abscess) + he said: "that's created more cells." She's not sure if this is true but is angry if it is as she thought it was cancer from the start but the doc said it was only an abscess.